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**Lifestyle Behaviour Change in Adults with Intellectual
Disabilities: An Exploratory Investigation of Carers'
Causal Attributions and Motivation to Support Change.**

Major Research Project
&
Clinical Research Portfolio

Volume I

(Volume II bound separately)

*Submitted in partial fulfilment of the requirement for the
Degree of Doctorate in Clinical Psychology.*

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ACADEMIC UNIT FOR MENTAL HEALTH AND WELLBEING



**University
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"At times our own light goes out and is rekindled by a spark from another person."

Albert Schweitzer

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**Does the Inclusion of Psychological Interventions
in Weight Loss Programmes Lead to Enhanced
Outcomes for Individuals with Overweight / Obesity
Who Have Intellectual Disabilities?**

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KEYWORDS: overweight, obesity, intellectual disabilities, psychological intervention

Prepared in accordance with the author guidelines for Obesity Reviews (See Appendix 1)

Abstract

Background

Overweight and obesity are more prevalent in adults with intellectual disabilities than in the general population^{1,2,3}. Despite this, there is limited research exploring the effectiveness of interventions for overweight / obesity in individuals with intellectual disabilities. This review aimed to examine whether the inclusion of psychological interventions led to enhanced weight loss outcomes and / or improved maintenance of weight loss in interventions for adults with intellectual disabilities and overweight / obesity.

Method

A systematic review of the published literature was undertaken to identify studies that evaluated weight loss interventions for adults with intellectual disabilities. Inclusion and exclusion criteria were utilised to identify relevant papers. The quality of all included studies was rated independently by two raters, using a specially designed scale.

Results

Eleven studies were identified that met the inclusion criteria for the review. Differences in study duration, means of reporting outcomes and duration of follow-up made it difficult to draw direct comparisons between studies. From the studies that were identified, there is no evidence to suggest that the inclusion of psychological interventions in weight loss programmes leads to

enhanced outcomes or improved maintenance of weight loss for individuals with intellectual disabilities and overweight / obesity.

Conclusions

Conclusions are limited by the fact that existing studies tend to be of poor quality. Further research is required to identify the factors that contribute most to weight loss as well as exploring potential barriers to weight loss; to further explore the utility of psychological interventions in weight loss programmes; and to examine the impact of social support on weight loss outcomes in adults with intellectual disabilities and overweight / obesity.

Introduction

Health problems associated with overweight / obesity present a major public health issue, which has reached epidemic proportions internationally. There is clear evidence that overweight / obesity has a negative impact upon health⁴, significantly increasing the risk of cardiovascular disease, diabetes, stroke and certain types of cancer⁵. Several studies exploring the prevalence of overweight / obesity in adults with intellectual disabilities have found that levels of overweight / obesity are higher in individuals with intellectual disabilities compared with levels of overweight / obesity derived from studies involving the general population^{1,2,3}. These findings highlight the need for effective interventions and clinical services for individuals with intellectual disabilities and overweight / obesity.

Clinical guidelines for the management of overweight / obesity provide recommendations on the delivery of interventions for individuals with overweight / obesity^{6,7}. A moderate, sustainable weight loss of 5 – 10kg or 5 – 10% of initial body weight has been shown to lead to significant clinical benefits, and so it is recommended that weight loss interventions aim for this degree of weight loss. To achieve this level of weight loss, clinical guidelines recommend that weight management interventions should be multicomponent, with three key components:

- supporting individuals to increase physical activity levels

- encouraging dietary changes to create an energy deficit diet of 600 kilocalories (kcal) per day
- the incorporation of psychological interventions to support sustained behavioural change

The incorporation of psychological interventions is supported by research that has found that the inclusion of cognitive behavioural or behavioural strategies led to improved outcomes for individuals with overweight / obesity engaged in weight loss interventions⁸. Accordingly, weight loss interventions have been developed for the general population, which have drawn upon a range of psychological interventions and tend to be delivered in combination with dietary advice and advice on increasing physical activity levels. Such interventions have been offered in both individual and group contexts.

Despite the increased prevalence of overweight / obesity that has been reported in individuals with intellectual disabilities, adults with intellectual disabilities can have difficulties accessing mainstream clinical services for overweight / obesity and weight management⁹. Individuals with intellectual disabilities may have increased support needs and experience higher degrees of social disadvantage than individuals in the general population. Therefore, it cannot be assumed that interventions and services designed for the general population will be effective when working with adults with intellectual

disabilities. Thus, it is important to develop and investigate the effectiveness of weight loss interventions for adults with intellectual disabilities¹⁰.

Hamilton *et al.* (2007) conducted a review of weight loss interventions for adults with intellectual disabilities and overweight / obesity¹⁰. The review found that, in contrast with research exploring weight loss interventions for the general population, relatively little research has looked at weight loss interventions for individuals with intellectual disabilities. Furthermore, few studies adopted a multicomponent approach, as is recommended by clinical guidelines on overweight / obesity. Generally, the weight loss interventions for adults with intellectual disabilities were mainly single component interventions, focused either on dietary change (focus on energy intake); physical activity (focus on energy expenditure) or health promotion (focus on education). Few studies included psychological interventions.

Given that the inclusion of psychological interventions in multicomponent weight loss programmes has been shown to lead to improved outcomes in terms of weight loss in the general population, it is important that research is conducted to explore the utility of such interventions when working with adults with intellectual disabilities and overweight / obesity. This systematic review aims to evaluate the current evidence in order to determine whether the inclusion of psychological interventions improves outcomes in weight loss interventions for adults with intellectual disabilities. In order to achieve this,

the outcomes of studies that include a psychological intervention as part of a weight loss programme for individuals with intellectual disabilities will be compared with studies that do not. The quality of evidence for the inclusion of psychological interventions in multicomponent weight loss interventions will be established and recommendations based on the findings will be made for future research in this area.

Objective

This systematic review aims to determine whether:

1. the inclusion of psychological interventions in weight loss programmes leads to enhanced outcomes for adults with intellectual disabilities who are overweight / obese.
2. the inclusion of psychological interventions enhances maintenance of weight loss.

Method

Search Strategy

A systematic literature search was conducted using the OVID online interface to access the Medline, Embase and Embase Classic databases; the EBSCO host online interface to access the PsycINFO and CINAHL databases and the Web of Science database. Databases were searched from start date to 31/01/2012.

Text word and subject heading searches were completed using terms relating to overweight / obesity, weight loss, weight maintenance and intellectual disabilities. Initially, search terms were matched to the subject headings in the relevant databases. Keyword searches of databases were also carried out. The results of searches were combined using the Boolean operators “AND” and “OR”. Duplicate results were removed. For full search strategy, see Appendix 2.

A sensitivity search was also carried out, which involved screening references from identified papers and from review papers, using the “cited by” function in electronic databases and conducting hand searches of relevant journals (Journal of Applied Research in Intellectual Disabilities, Journal of Intellectual and Developmental Disability, Journal of Intellectual Disability Research, American Journal on Intellectual and Developmental Disabilities, Mental Retardation).

Inclusion / exclusion criteria

For each paper identified from the database searches, titles were screened against inclusion and exclusion criteria to allow for removal of irrelevant articles.

Inclusion Criteria:

- Studies published in English

- Studies published in peer-reviewed journals
- Studies that included individuals with intellectual disabilities
- Studies that included adults (age 16 and over)
- Studies that included individuals with overweight / obesity
- Studies that measured weight change by any method (e.g. change in Body Mass Index (BMI), reduction in kg)
- Experimental studies that did not involve surgical or pharmacological interventions

Exclusion Criteria:

- Studies not published in English
- Studies not published in peer-reviewed journals
- Qualitative studies; case studies
- Reviews, dissertation abstracts, conference abstracts, poster presentations / abstracts
- Studies that did not include a weight outcome measure

Qualitative studies and case studies were excluded as it was felt that it would be difficult to generalise and integrate findings from these whilst aiming to achieve the objectives set for this review. Abstracts were reviewed for articles where it was unclear from the title whether or not they were suitable for inclusion in the review. Following exclusion of unsuitable articles, a total of 29 articles were left. Full text copies of these were obtained.

Following review of the 29 articles for which full text copies were obtained, a further 18 articles were excluded. Reasons for exclusion included not indicating whether participants were overweight / obese (2); including participants of normal weight in interventions (9); no measure of weight change included (1); not intervention study (5); case study (1). Further details of excluded studies are provided in Appendix 3. This left a total of 11 papers that were suitable for inclusion in the current review. The process for identifying papers is outlined in Figure 1.

{Insert Figure 1 here}

Quality criteria

The quality of the 11 papers deemed suitable for inclusion in the review was assessed using a quality rating scale (see Appendix 4) which was developed specifically for this review. The Consolidated Standards of Reporting Trials guidelines¹¹ and established guidelines published by the Scottish Intercollegiate Guidelines Network¹² were consulted when developing the rating scale and quality criteria. Using the quality rating scale, each study was assessed on 25 items relating to the design and method. Studies were awarded a score of 0 to 60, with higher scores reflecting greater quality. Scores were then used to allocate studies to one of four categories reflecting overall study quality.

All papers were rated by two reviewers, independently. Full agreement on the overall quality rating was achieved on 8 of the 11 papers (73%). Rating of the three remaining papers was resolved following discussion.

Results

A summary of the included papers, including main findings and quality rating achieved is presented in Table 1.

{Insert Table 1 here}

Inclusion of psychological interventions

The standard of reporting of the content of interventions varied across studies. This made it difficult to determine, in some cases, whether psychological interventions had truly been incorporated. To facilitate decision making, it was decided that studies that appeared to have included psychological interventions would be checked against the taxonomy of behaviour change techniques described by Michie *et al.* (2011)¹³. This provides labels and definitions for behaviour change techniques, such as those commonly incorporated in weight loss interventions.

Studies that did not include psychological interventions

Three studies^{14, 15, 16} described interventions whereby the focus was on diet and / or physical activity, but did not include psychological interventions to promote behaviour change. Marshall *et al.* (2003) adapted content from

materials designed by the health promotion agency in Northern Ireland to improve healthy eating and exercise patterns; Bradley (2005) used educational materials covering healthy eating; Geller & Crowley (2009) used an empowerment group model, with activities that tended to focus on increasing activity levels and on healthy eating. The studies and their main findings are described below.

Marshall *et al.* (2003) evaluated the impact of health promotion classes on weight loss in adults with intellectual disabilities and overweight / obesity. Classes were delivered in group settings, led by nurses, and topics focused on healthy eating as well as exercise. Participants were day centre attendees. Three groups were delivered and the length of programme varied; for two groups, six, weekly sessions were held and for one group, eight, weekly sessions were held. The rationale for the variation in duration was not addressed. Twenty individuals with overweight / obesity attended the programme. Participants' weight was measured at each session. At the outset, mean weight was 85kg (SD = 19.4) and mean BMI was 33.5 (SD = 5.9). This reduced to a mean weight of 81.6kg (SD = 17.8) and a mean BMI of 31.9 (SD = 5.4) over a six-week period. As no follow-up data was collected, it is not possible to determine whether or not weight reductions were maintained over time.

Bradley (2005) described the outcomes of a dietician-led course for adults with intellectual disabilities, which focused on improving eating patterns. Eight individuals with overweight / obesity attended the course. A total of 34 sessions were held, with each session lasting 90 minutes to two hours. Weight measurements were taken at each session. Of the eight individuals with obesity (BMI of 30 or greater) who attended the course, one individual's weight increased by 7.1kg, which was attributed to medication change. This individual was subsequently excluded from analysis. Average weight loss for the remaining seven participants was 6.2kg (range: +2.2kg to -15.5kg). Mean BMI at the outset of the programme was 37.7 (range = 33.5 to 43.5). This had decreased to 34.7 (range = 28 - 39) by the end of the programme. Limitations associated with this study included the fact that there was no follow-up so it was not possible to determine whether the weight loss was maintained. Moreover, whilst exercise was not an explicit component of the programme, participants were encouraged to increase activity levels and engage in community exercise facilities. As this was not controlled for, it is possible that this might have had an impact on participants' weight loss and may, therefore, have confounded results.

Geller & Crowley (2009) explored the effectiveness of an empowerment group model, which aimed to reduce participants' feelings of loneliness and stress by supporting them to develop more positive interactions with their environment. It was hypothesised that this would result in successful weight

loss and maintenance. Forty-five individuals with intellectual disabilities and overweight / obesity were recruited from a day centre. Participants attended the group for an hour, once or twice a week. Group sessions consisted of activities designed to create feelings of community, success and of being important, which also tended to focus on increasing activity levels and on healthy eating. In addition to attending the group, participants met with a clinician every one to two months. At these meetings, weight, activity levels and diet were assessed. Two participants dropped out. Of the remaining 43 participants, the average weight at the start of the programme was 173.12lbs (SD = 35.20). The average participant attended the group for 13.5 months (SD = 6.4 months). The average weight at the end of the programme was 170.51lbs (SD = 33.63), representing a loss of 2.6lbs. As other factors at the day centre or at home might have had an impact on participants' weight, it is not certain that attendance at the group directly resulted in weight loss. Since there was no control group, this was difficult to evaluate.

Studies that included psychological interventions

Eight studies^{17, 18, 19, 20, 21, 22, 23, 24} described the inclusion of psychological interventions, which met the descriptions provided in the taxonomy of behaviour change techniques described by Michie *et al.* (2011)¹³.

Four studies explored the effectiveness of a behaviour therapy intervention for adults with intellectual disabilities^{17, 18, 19, 22}. Each of these studies based

their intervention on a behavioural programme developed by Rotatori & Fox (1981)²⁵, which aims to change the eating habits, activity levels and self-reinforcement patterns of individuals by gradually introducing new behavioural strategies. A key behavioural strategy included in this programme is self-monitoring, whereby participants are asked to keep food diaries. Participants are taught to change dietary patterns by following specific guidance, e.g. restricting meal consumption to one location in the home, reducing the rate of eating and amount eaten and reducing snacking behaviour. Physical activity patterns are targeted by recommending simple changes to everyday activities and encouraging increased exercise participation. Attendance at sessions, encouragement and motivation to lose weight is supported with the use of reinforcement and reward strategies (e.g. entering participants into prize draws in return for attendance at programmes; presentation of weight loss certificates). This intervention does not, however, include an energy deficit diet, which is advocated by the clinical guidelines on the management of overweight / obesity^{6,7}.

Of the studies utilising this programme, the length of interventions varied from 10 to 14 weeks. Across all studies, the intervention was delivered in group sessions. The studies are described in more detail below.

Fox *et al.* (1984) evaluated the effectiveness of a 10 week treatment programme for adults with intellectual disabilities. Illustrated materials were

developed to facilitate the learning and practice of behavioural weight loss strategies. The study also aimed to evaluate the impact of a buddy reinforcement system on weight loss and / or weight maintenance. Sixteen adults with moderate intellectual disabilities, all of whom were at least 10% above their desirable weight, volunteered to participate in the programme. Eight participants were randomly assigned to a behaviour therapy group and eight participants were randomly assigned to a behaviour therapy plus buddy reinforcement group.

During the 10 week behaviour therapy only programme, group sessions, lasting an hour, were held twice weekly. Daily homework assignments were set to encourage practice of the behavioural techniques. Following the weight loss phase, a maintenance phase lasting five weeks commenced, with meetings taking place once a week. At one year post conclusion of the maintenance phase, weights were obtained for all participants.

Individuals in the buddy reinforcement plus behaviour therapy group received the same treatment and maintenance component as individuals in the behaviour therapy only group. In addition, participants in this group were also paired into "buddy teams", which were designed to lead to enhanced social recognition, with associated extra reinforcement and rewards. Participants were encouraged to help their buddy with the

programme through phone calls at home and personal contacts at a work placement.

At the end of the 10 week treatment programme, participants in the behaviour therapy group lost an average of 7.3lbs (range: -1 to -16lbs). Participants in the buddy reinforcement behaviour therapy group lost an average of 8.2lbs (range: -3 to -17lbs). The differences between groups were not significant. Participants were followed up at the end of the five week maintenance programme. Participants in the behaviour therapy group lost an average of 2.1lbs (range = +2 to -5lbs). Participants in the buddy reinforcement behaviour therapy group lost an average of 2.3lbs (range = +1 to -6lbs). No significant differences were observed between the groups in terms of weight loss. At follow-up one year post maintenance, of the two groups combined, overall six individuals had maintained weight loss. The mean weight loss for these individuals was 12.8lbs (range = -3 to -33lbs). The remaining individuals either maintained their baseline weight or gained weight. Mean weight change was +3.9lbs (range = 0 to +10lbs).

Fox *et al.* (1985) explored the impact of parent involvement on success in a 10-week behavioural weight loss programme for adults with intellectual disabilities and overweight / obesity. Sessions lasting one hour each, were delivered twice weekly. Fifteen individuals volunteered to participate in the programme; all participants were employed in a sheltered workshop setting

and lived with their parents. Participants were divided into two groups; in one group, parents were instructed to be actively involved in encouraging, assisting and rewarding programme strategies, whereas parents of individuals in the other group were only given a description of the programme content and were not explicitly instructed about supporting and reinforcing the aims of the programme.

Following the 10 week intervention, participants in the parent involvement condition had lost an average of 7.4lbs (range = -4 to -11lbs). Participants in the group where parents had not been actively encouraged to be involved lost an average of 2.4lbs (range = +5 to -8lbs). At three month follow-up participants whose parents had been actively involved maintained an average weight loss of 3.4% of initial weight, compared with 1.6% of initial weight for those whose parents had not been actively involved. At six month follow-up, individuals in the parent involvement group had maintained an average percentage weight loss of 2.17% compared to a 1.58% gain for those whose parents had not been actively involved.

McCarran & Andrasik (1990) also explored the impact of parent / carer involvement in a weight loss programme for adults with intellectual disabilities. The programme consisted of three, one hour treatment sessions per week for 14 weeks, followed by two, one hour maintenance sessions per week, for five weeks. Participants were randomised to one of two groups; in

one group, parents / carers received frequent contact from the group leader; in the other group, parents / carers had no input other than initial notification. Twelve participants initially volunteered to take part in the study, however four subsequently dropped out.

Analysis of weights for the two groups revealed that, although the group whose parents / carers were involved obtained greater average weight losses (mean = 5.5lbs) than the group whose parents / carers were not actively involved (mean = 2.7lbs), this was not a statistically significant difference. At one year follow-up, individuals whose parents / carers had been actively involved had maintained an average weight loss of 3.4lbs. Conversely, individuals whose parents / carers had not been actively involved had gained an average of 1.1lbs.

Sailer *et al.* (2006) examined the effectiveness of a 10 week, behavioural weight loss treatment programme for adults with mild intellectual disabilities who were living independently in the community. Six adults with mild learning disabilities, all of whom were obese (BMI of 30 or over) and had expressed interest in losing weight, were referred for participation by case managers. Sessions lasted approximately one hour each and were held weekly. A therapist support component was also included as part of the programme; each week between sessions, participants received a phone call from a therapist with the purpose of addressing any questions that the individual

had about the behavioural techniques introduced in the group and to encourage them to keep applying what they had learned in group sessions.

Participants were weighed at each group session and at two, three and four weeks post intervention. Over the course of the 10 week programme, the average weight loss was 5.5lbs, with a range of +1lbs to -18lbs. By four week follow-up, the average weight loss from baseline was 3.4lbs; with a range of +5lbs to -13lbs.

Four studies explored the effectiveness of multi-component weight loss programmes that included psychological interventions^{20, 21, 23, 24}. Psychological interventions utilised in these studies were mainly behavioural techniques, including offering praise and other incentives for weight loss; self-monitoring of food intake and weight; stress reduction; communication training; work on enhancing motivation to change; cognitive restructuring; stimulus control; problem solving; goal setting; relapse prevention strategies. The length of interventions varied from eight weeks to twelve months and was delivered in group sessions^{20, 21, 24} or on an individual basis²³. The studies are described in more detail below.

Ewing *et al.* (2004) evaluated the impact of an eight-week educational programme, which aimed to promote healthy behaviours and to decrease BMI, for adults with intellectual disabilities and overweight / obesity. Topics for the classes included nutrition, exercise, stress reduction and cognitive

restructuring, communication, motivation to change and relapse prevention strategies. In addition, advice on healthy eating and exercise was provided. Sessions lasting 90 minutes were held weekly and were followed by an optional instructor-led brisk walk. In addition to the classes, participants were offered two to four home visits to establish an individual exercise plan, to develop a dietary plan and to make a visit to a grocery store to identify healthy choices.

One hundred and fifty four individuals with intellectual disabilities started the programme; 29 dropped out and incomplete data was available for 33 others, leaving a final sample size of 92 individuals. Mean BMI at the start of the programme was 35.4 (SD = 7.06). By the end of the programme, 18.5% of individuals had decreased their BMI by 0.75 units or more (approximately 5lbs for women and 7lbs for men).

Mann *et al.* (2006) evaluated the effectiveness of a health promotion intervention for adults with intellectual disabilities and overweight / obesity, which comprised eight classes and covered a range of topics, including nutrition, exercise, stress reduction, communication, motivation to change and relapse prevention strategies. The goal of the programme was to increase healthy eating and physical activity, thus, weight loss was not an explicit goal, but was highlighted as a likely outcome if the primary aims were achieved. Classes were 90 minutes in length and were followed by an optional

instructor-led brisk walk. Additionally, all participants were offered two home visits to establish an individual exercise programme, develop a dietary plan and make a visit to a grocery store to identify healthy food choices. Participants' height and weight were measured at the beginning and end of the programme.

Three hundred and twenty four participants were recruited into the study. 66 individuals dropped out of the programme and data for 66 further participants was incomplete, meaning that they could not be included in the analysis. Thus, analysis was based on outcomes for 192 individuals who completed the programme. Mean BMI at baseline was 35.38 (SD = 6.85). Mean BMI at the end of the programme was 35.07 (SD = 6.59), representing an average BMI reduction of 0.31. In 26% of overweight / obese participants, programme participation was associated with weight reduction of at least 0.8 BMI (approximately 2.3kg).

Melville *et al.* (2011) examined the effectiveness of a multi-component weight loss intervention for adults with intellectual disabilities and obesity. The intervention was delivered on an individual basis, and family / paid carers were involved to support participants, where appropriate. The intervention comprised nine sessions, lasting 40 – 60 minutes each, which took place every 2 – 3 weeks. Participants were given a personalised dietary prescription with a daily 600kcal energy deficit, and advice on increasing activity to meet the

minimum exercise recommendations was provided. In addition, psychological interventions, including goal setting and self-monitoring, techniques to maintain motivation, cue avoidance, stimulus control and problem solving, were incorporated into each session. Body weight and BMI were measured before and after the intervention (approximately 24 weeks after baseline measurements were obtained).

Fifty four individuals consented to participate; 47 completed the intervention. Mean weight at baseline was 100.6kg (SD = 26.8). This reduced to 96.1kg (SD = 26.9) at the end of the programme, representing a reduction of 4.47kg (SD = 4.75). Mean BMI at baseline was 40.0 (SD = 8.03). This reduced to 39.2 (SD = 8.2) by the end of the programme, a decrease of 1.82 BMI points. Of the 47 participants who completed the intervention, 17 (36.17%) lost 5% or more of their initial weight from baseline.

Saunders *et al.* (2011) described the outcomes of a diet and physical activity intervention, which aimed to establish healthy food and beverage consumption in adults with intellectual disabilities and overweight / obesity. The intervention consisted of an initial meeting which was carried out on a one-to-one basis to explain the diet, which aimed for a daily intake of 1200 – 1300 calories per day and advocated the use of meal replacement shakes and low calorie frozen meals. This was followed by a six-month diet phase, comprising monthly meetings, where height, weight and waist circumference

were measured. Behavioural techniques were utilised and included offering praise and other incentives (e.g. certificates, stickers) for weight loss. In addition, financial incentives were offered for completing rating scales and to reward weight loss. Participants were encouraged to record weight, food intake and exercise patterns. There was an optional physical activity component. The six-month diet phase was followed by a six-month follow-up phase, during which participants were encouraged to continue following the diet if they wished to lose further weight, and advised on how to continue a healthy eating pattern whilst increasing calorie intake, if not.

Seventy three individuals completed the six-month diet phase. The average BMI at the outset was 38.0. The average weight loss over the six-month diet phase was 6.0kg. Forty three participants completed the six-month follow-up phase. Of these participants, the average cumulative weight loss was 8.8kg, although the range of weight lost varied widely, from 23.2kg lost to 5.8kg gained.

Does the inclusion of psychological interventions lead to enhanced weight loss?

Variations in the reporting of outcome data made comparison between studies difficult. Two studies^{20, 21} reported weight loss in terms of BMI reductions. This prevented direct comparison with the other studies, which reported mean weight loss in pounds or kilograms. For studies which reported mean weight loss in pounds, the outcomes were converted to

kilograms to allow comparison between studies. The mean weight loss in kilograms for each study is presented in Figure 2.

{Insert Figure 2 here}

In addition, percentage weight loss was calculated for each study, which allowed the outcomes of the Mann *et al.* (2006) study to be included in the comparison. As Ewing *et al.* (2004) did not report mean baseline weight, it was not possible to calculate percentage weight loss for this study. Percentage weight loss for each study is shown in Figure 3.

{Insert Figure 3 here}

There was a wide range in mean weight loss between studies. Weight loss in studies that did not include psychological interventions ranged from 1.2kg to 6.2kg, and 1.5% to 6.3% of baseline weight. Weight loss in studies that included psychological interventions ranged from 1.1kg to 6.0kg and 0.9% to 6.3% of baseline weight. There were also wide variations in study duration, and in how and when data was collected, which might have contributed to the variations in findings that were observed, and limited comparisons between study outcomes. Overall, however, the pattern of results across studies does not provide clear evidence that the inclusion of psychological

interventions leads to enhanced outcomes in weight loss interventions for adults with intellectual disabilities.

Does the inclusion of psychological interventions enhance maintenance of weight loss?

Six studies^{14, 15, 16, 20, 21, 23} did not include a follow-up to assess whether weight loss was maintained after the intervention had been completed. Five studies did include a follow-up, however, the length of time between end of intervention and follow-up varied widely, from four weeks to one year.

Fox *et al.* (1984) conducted a follow-up one year after the end of their intervention. They found that six individuals (37.5%) had maintained weight loss. Fox *et al.* (1985) conducted a follow-up six months post-intervention. They found that individuals whose parents had been involved in the intervention had maintained an average weight loss equivalent to a 2.17% reduction in body weight. Individuals whose parents had not been actively involved in the intervention, conversely, had gained weight, equivalent to a 1.58% increase in average body weight. Similar findings were observed by McCarran & Andrasik (1990), who conducted a follow-up one year post-intervention and found that individuals whose parents / carers had been involved in the intervention maintained an average weight loss of 3.4lbs, whereas individuals whose parents / carers had not been actively involved gained, on average, 1.1lbs. Sailer *et al.* (2006) conducted a follow-up four

weeks post-intervention and found that mean weight loss from baseline was 3.4lbs, compared to a mean weight loss of 5.5lbs from baseline at the end of intervention, which suggests that participants had begun to regain weight following the end of the intervention. Saunders *et al.* (2011) conducted a follow-up six months after the end of intervention. At follow-up, mean weight loss from baseline was 8.8kg, compared with 6.0kg from baseline at the end of the intervention. However, there was a wide variation in the range of weight lost (-23.2kg to +5.8kg).

Of the studies that did not include psychological interventions, none included a follow-up period. This meant that it was not possible to determine whether or not the inclusion of psychological interventions was associated with enhanced outcomes in terms of maintenance of weight loss. Of the studies that included psychological interventions, duration of follow-up varied widely between studies. Overall, results are somewhat conflicting; in some studies, weight loss appears to have been maintained; however, there was also some indication of individuals regaining weight following the end of intervention²².

Discussion

Studies varied widely in terms of design and delivery of interventions. The length of intervention varied from six weeks to 13.5 months, and not all studies included a maintenance condition. The variation in methodology and

in reporting of outcomes makes it difficult to draw comparisons between the studies; the differences are such that it has not been possible to undertake a meta-analysis of outcomes.

The Quality Rating Tool developed for this study was adapted from existing rating scales, including the Consolidated Standards of Reporting Trials guidelines¹¹ and established guidelines published by the Scottish Intercollegiate Guidelines Network¹², which tend to have been developed for studies such as Randomised Controlled Trials. When rating the studies included in this review, it was found that many of these did not meet the criteria that might be expected of a more rigorous study design. This meant that the Quality Rating Tool lacked sensitivity, and did not really allow for meaningful differentiation of included studies.

Overall, the quality of studies investigating weight loss interventions for adults with intellectual disabilities and overweight / obesity is poor. The majority of studies utilised uncontrolled, before and after designs. The lack of control groups makes it difficult to fully evaluate the impact of weight loss interventions and to ascertain whether or not weight loss was a direct result of participation in the intervention. Few studies supported individuals to achieve the recommended clinically significant weight loss of 5 – 10kg or 5 – 10% of body weight. Sample sizes in some studies were very small, which might limit the generalizability of findings. Descriptions of methodology

varied widely across studies, and were generally poor, which made it difficult to fully assess the quality of design. Furthermore, no studies included a measure of adherence to the treatment protocol.

There was a considerable variation in the amount of weight lost between individuals in each study. Few studies sought to examine factors that might contribute to and / or impede weight loss. Moreover, no studies included a measure of adherence to the intervention. Adherence of individuals and parents / carers to the programme between sessions is undoubtedly linked to outcomes. Future research should aim to ascertain the factors that contribute most to weight loss as well as exploring potential barriers to weight loss.

Psychological interventions

Psychological interventions utilised were predominately behavioural techniques, such as relapse prevention strategies, goal setting, motivation enhancement strategies, problem solving and stimulus control. Self monitoring was facilitated using food intake and weight record charts and reward systems were used to motivate behavioural changes. Inconsistencies in the reporting of methodologies of studies made it difficult to determine the extent to which different components were emphasised. The variable quality of reporting of interventions will not only impact upon the ability to fully evaluate findings but also upon the ability to replicate studies.

Research investigating weight loss interventions for individuals with overweight / obesity who do not have intellectual disabilities has demonstrated that Cognitive Behaviour Therapy (CBT) leads to enhanced weight loss and weight maintenance⁸. There has been no research exploring the utility of CBT approaches for weight loss in individuals with intellectual disabilities. In addition, research focusing on the general public has begun exploring the utility of a range of different psychological approaches in the field of weight management with promising outcomes. For example, mindfulness based interventions have been shown to be effective in facilitating weight loss²⁶. There has been one preliminary study investigating the application of mindfulness techniques to weight loss in individuals with Prader-Willi Syndrome²⁷. This described a series of case studies with three adolescent males, who had mild intellectual disabilities and a BMI in the obesity range. The intervention was delivered on an individual basis and lasted until each participant had reached their ideal body weight (two to five years) and was followed by a three year maintenance phase. All individuals managed to reduce their body weight to within the healthy range, and weight loss was maintained over the three year maintenance phase. Whilst this was a very time and resource intensive intervention, which is unlikely to be replicated in healthcare settings, it does suggest that mindfulness-based interventions may be an effective intervention for overweight / obesity in individuals with intellectual disabilities. Further research is required to further explore this area.

Impact of social support

A key finding from the studies examining the effects of parent / carer involvement was that parent / carer involvement leads to enhanced maintenance of weight loss, with a lack of active parent / carer involvement being associated with weight gains following the end of intervention^{18, 19}. These results indicate that parent / carer involvement might be an important factor impacting on success in weight loss interventions. This should be further explored in future research.

Limitations of review

The overall poor quality of studies reviewed; along with the wide variations in design and lack of follow-up data make it difficult to draw firm conclusions about the effectiveness of the inclusion of psychological interventions in weight loss programmes for adults with intellectual disabilities and overweight / obesity. The wide variations across studies meant it was not possible to conduct a meta-analysis as this would have had little practical meaning; however, this also limits the ability to draw conclusions.

Conclusion

Overall, the majority of studies have a number of significant limitations, which means that it is difficult to draw firm conclusions about the effectiveness of the inclusion of psychological interventions in weight loss interventions for adults with intellectual disabilities and overweight / obesity.

Suggestions for future research

Given the high rates of overweight / obesity observed in adults with intellectual disabilities, there is a need to develop effective weight management interventions based on the recommendations of national clinical guidelines, so it is important that the evidence base in this area is further developed and refined.

There is a need for further research into the effectiveness of interventions, the inclusion of psychological interventions, and the impact of parent / carer involvement. Future research should aim to overcome the limitations highlighted in the research to date. It is important that future studies include follow-up periods to examine weight loss maintenance. In addition, attrition rates should be reported and reasons for withdrawal ascertained to allow factors affecting programme adherence to be further explored. Studies have shown that parent / carer involvement can be a critical factor in determining success in weight loss interventions. The best way of incorporating parent / carer involvement should be explored.

Studies investigating the different components of weight loss interventions are required in order to determine what actually aids weight loss, alongside establishing the length and timing of treatment required. Any new studies in this area should pay particular attention to the design and subsequent

reporting of their study. Recommendations for future research are provided in Table 2.

{Insert Table 2 here}

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Table 1: Summary of included papers

Study	Type of study	Included psychological intervention?	n	Participant demographic information			Weight loss measure	Baseline weight	Included Follow up?	Main results	Were results significant?	Quality rating
				Age (mean)	Gender	Level of ID						
Fox et al. (1984)	Randomised controlled trial	Yes	16	28.5 years	7 male; 9 female	4 mild; 12 moderate	lbs	170.7lbs	Yes (12 months)	Behaviour therapy condition: mean weight loss of 7.3lbs (range: -1 to -16lbs) Buddy reinforcement condition: mean weight loss of 8.2lbs (range: -3 to -17lbs).	Yes (p<0.0001)	B
Fox et al. (1985)	Non-randomised controlled trial	Yes	15	28 years	11 male; 4 female	15 moderate	lbs	168.1lbs	Yes (10 weeks)	Parent involvement group: mean weight loss of 7.4lbs (range: -4 to -11lbs) Non-parent involvement group: mean weight loss of 2.4lbs (range: +2 to -8lbs).	Yes (p<0.0001)	C
McCarran & Andrasik (1990)	Case-controlled study	Yes	8	29 years	1 male; 7 female	7 mild; 1 moderate	lbs BMI	168.2lbs	Yes (12 months)	At one year follow-up: Parent involvement group: mean weight loss of 3.4lbs Non-parent involvement group: mean weight gain of 1.1lbs.	Yes (p<0.01)	C

Table 1: Summary of included papers (continued)

Study	Type of study	Included psychological intervention?	n	Participant demographic information			Weight loss measure	Baseline weight	Included Follow up?	Main results	Were results significant?	Quality rating
				Age (mean)	Gender	Level of ID						
Marshall et al. (2003)	Before-after study	No	20	37 years	14 male; 6 female	Not reported	kg BMI	85kg	No	Mean weight loss of 3.4kg; mean BMI reduction of 1.6 points.	Yes (p<0.001)	C
Ewing et al. (2004)	Case-controlled study	Yes	92	39.7 years	42 male; 50 female	Mean IQ: 50.2	BMI	209.5lbs	No	By end of programme, 18.5% had reduced BMI by 0.75 units or more.	Not reported	C
Bradley (2005)	Before-after study	No	7	Not reported	7 female	Not reported	kg BMI	93.2kg	No	Mean weight loss of 6.2kg (range = +2.2kg to -15.5kg).	Yes (p<0.05)	C
Mann et al. (2006)	Before-after study	Yes	192	38.6 years	64 male; 128 female	Mean IQ: 50.7	BMI	BMI: 34.9	No	Mean BMI reduction of 0.31 points.	Yes (p<0.01)	C
Sailer et al. (2006)	Before-after study	Yes	6	46 years	2 male; 4 female	6 mild	lbs	252lbs	Yes (10 weeks)	Mean weight loss of 5.5lbs (range: +1 to -18lbs).	Not reported	C
Geller & Crowley (2009)	Before-after study	No	43	42.6 years	18 male; 25 female	Not reported	lbs	173.1lbs	No	Mean weight loss of 2.6lbs.	No (p=0.14)	C
Melville et al. (2011)	Before-after study	Yes	54	48.3 years	22 male; 32 female	17 mild; 17 moderate; 20 severe	kg BMI	100.6kg	No	Mean weight loss of 4.47kg (SD = 4.75); mean BMI reduction of 1.82 points.	Yes (p<0.0001)	B
Saunders et al. (2011)	Before-after study	Yes	73	Not reported	30 male; 43 female	Not reported	lbs BMI	BMI: 38.0	Yes (6 months)	Mean weight loss of 6.0lbs.	Not reported	C

Table 2: Recommendations for future research

- Ensure that design of intervention is adequately described.
- Include a sample size power calculation to ensure sufficient power.
- Include both weight loss and maintenance phases, with a minimum follow-up time of 12 months from baseline.
- Ensure clear reporting of outcomes, including a measure of weight, BMI and percentage weight loss.
- Utilise controlled studies.

Figure 1: Flowchart outlining the process for the identification of papers

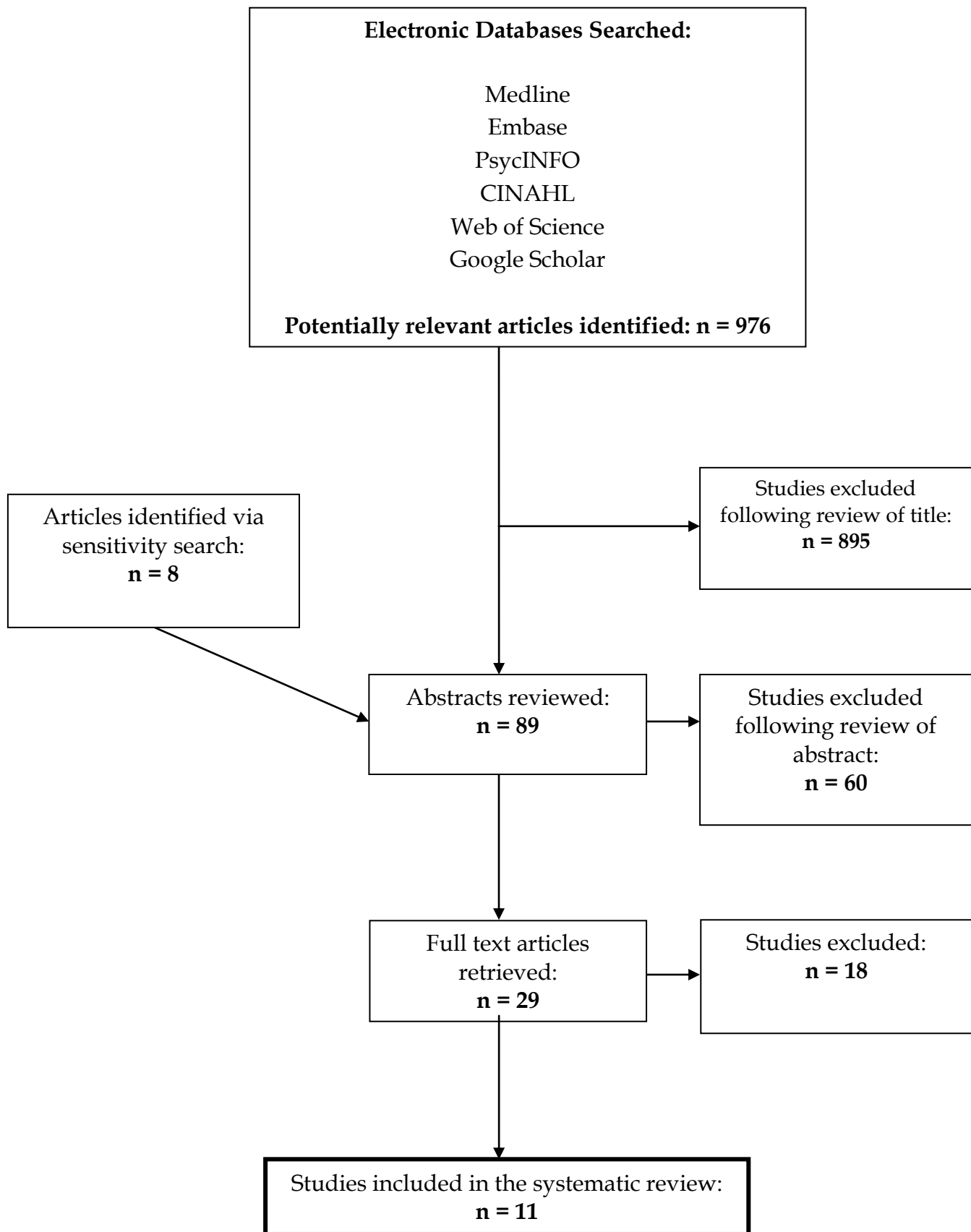
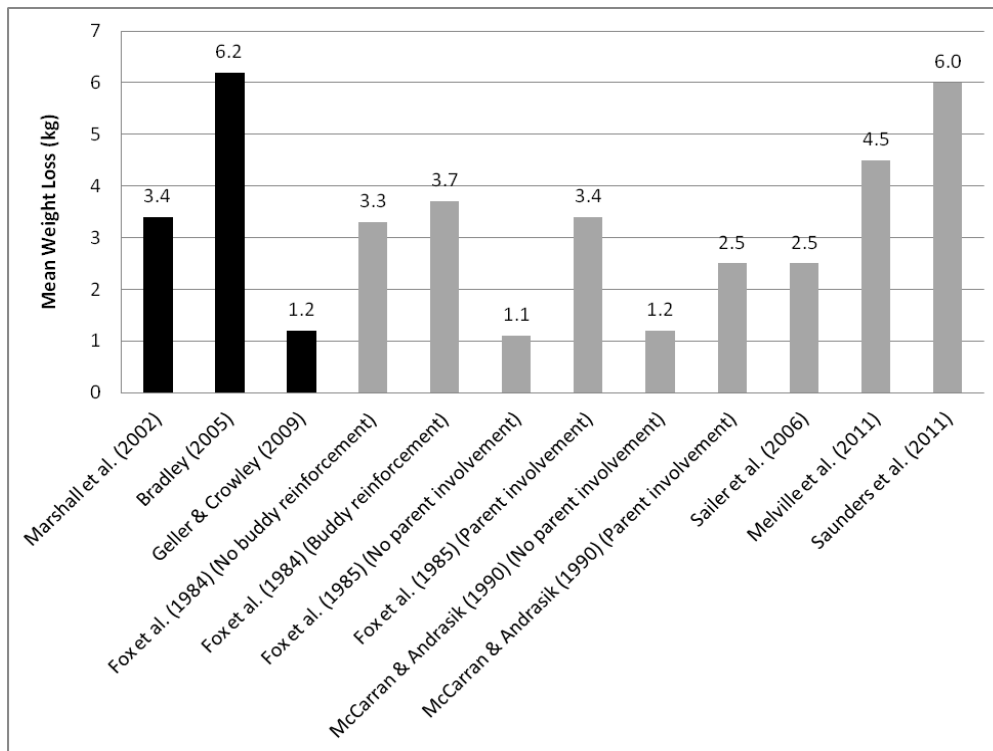
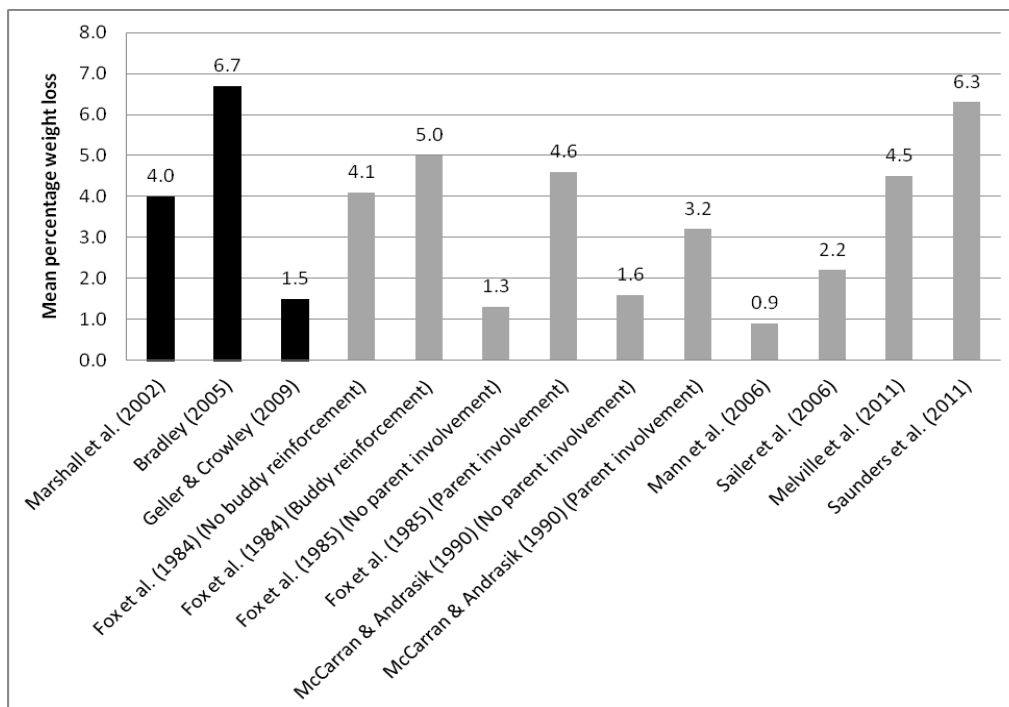


Figure 2: Mean weight loss in kg by study



NB. Studies which did not include a psychological intervention are indicated by black bars; studies which included a psychological intervention are indicated by grey bars.

Figure 3: Mean percentage weight loss by study



NB. Studies which did not include a psychological intervention are indicated by black bars; studies which included a psychological intervention are indicated by grey bars.

**Lifestyle Behaviour Change in Adults with Intellectual
Disabilities: An Exploratory Investigation of Carers'
Causal Attributions and Motivation to Support Change.**

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Prepared in accordance with the author guidelines for Journal of Applied Research in Intellectual Disabilities (See Appendix 4)

Abstract

Background Carers and families have a key role in supporting adults with intellectual disabilities to make lifestyle behaviour changes. This study explores paid and family carers' motivation to support change and their attributions around physical activity choices in the individuals that they support.

Methods A between subjects questionnaire design, using two questionnaires adapted specifically for this study, was used to investigate carers' motivation to support behaviour change and explore how this related to their attributions of physical activity choices. The influence of gender, age and level of intellectual disabilities of the individual that the carer supports were examined.

Results 18 carers participated in the study. There was evidence to suggest that carers' motivation to support change and attributions were correlated. In addition, motivation and attributions were related to age and level of intellectual disabilities of the individual supported by the carer.

Conclusion Carer attributions might present a barrier to motivation to support change. This may indicate a training need for carers. Further research is required to further explore carer attributions and to further examine the utility of the questionnaire measures adapted for this study.

Lay summary

Adults with intellectual disabilities are more likely to be overweight or obese than adults who do not have intellectual disabilities. Being overweight or obese can mean that an individual has a higher risk of developing a range of health problems.

Taking part in physical activity can help to prevent the development of health problems and can also help reduce weight. However, adults with intellectual disabilities generally do not lead very active lifestyles. This suggests that there is a need to develop services that can support adults with intellectual disabilities to make changes to their lifestyles, such as becoming more active.

Many adults with intellectual disabilities rely on carers to help them to access services. What carers think about services might have an impact on whether they think it is important to help the person that they support to access these and to make changes to their lifestyle.

The aim of this study was to explore carers' motivation to support the individuals that they care for to make changes to their physical activity levels. It also aimed to explore what carers think about the physical activity choices of the adults with intellectual disabilities that they support.

This study found that there was some evidence to suggest that the way that carers think about physical activity choices might influence whether or not they think that it is important to support the individual that they care for to make changes to these. As well as this, it was found that what carers think about physical activity choices differed depending on the age and level of intellectual disability of the individual that they support. The age and level of intellectual disability of the individual supported by the carer also influenced whether or not carers felt it was important to support the individual to make changes. Carers of older individuals and individuals with more severe intellectual disabilities were less likely to say that they thought that it was important for the individual to be more active.

The findings suggest that the way that carers think about physical activity choices might stop them from supporting individuals with intellectual disabilities to access services. This might mean that training for carers to help them to see the importance of physical activity would be of benefit to the individuals with intellectual disabilities that they support.

Introduction

Adults with intellectual disabilities have been shown to experience health inequalities compared with the general population, including higher rates of physical health problems (NHS Health Scotland, 2004). The risk of developing a number of health problems, including cardiovascular disease, type 2 diabetes, hypertension, osteoarthritis and cancer, has been linked to obesity (World Health Organisation, 2000) and there is clear evidence that obesity has a negative impact upon health (Kopelman, 2007). While obesity has been recognised as a major public health concern internationally (World Health Organisation, 2004), several studies examining the prevalence of obesity in individuals with intellectual disabilities have found that rates of obesity are higher compared with rates of obesity from studies involving the general population (Emerson, 2005; Melville *et al.*, 2006; Melville *et al.*, 2008).

Engaging in regular physical activity has been shown to be protective against the development of many health problems (World Health Organisation, 2002). However, in addition to the increased prevalence of obesity, studies have shown that adults with intellectual disabilities tend to lead more sedentary lifestyles and be less physically active than individuals in the general population (Temple & Walkley, 2003; Emerson, 2005). Finlayson *et al.* (2009) investigated the participation of individuals with intellectual disabilities in physical activity. It was found that individuals with intellectual disabilities were significantly less likely than the general population to meet the

recommended levels of physical activity set out by the Scottish Executive (2003). Only five percent of the total sample met the recommendation of at least 30 minutes of at least moderate activity on a minimum of five days per week, compared with 39% of the sample from the general population in the Scottish Health Survey (Scottish Government, 2010).

Thus, findings indicate a higher prevalence of obesity and lower levels of physical activity among individuals with intellectual disabilities compared with the general population. This highlights the need for effective interventions and clinical services to support lifestyle behaviour change in individuals with intellectual disabilities. However, individuals with intellectual disabilities may have problems accessing mainstream clinical services, such as those targeting obesity and weight management (NHS Health Scotland, 2004). It is, therefore, important to develop and investigate the effectiveness of lifestyle behaviour change interventions for individuals with intellectual disabilities.

Carer involvement

Many individuals with intellectual disabilities are supported by carers to identify their health needs and access services. In addition, carers have a key role in supporting the individual that they provide care for to make healthy lifestyle choices (Hamilton *et al.*, 2007). It is, therefore, vital that carers are able to recognise the health risks associated with obesity and low physical activity levels, and the benefits associated with interventions that promote and support

healthy lifestyle choices. In addition, carers need to be prepared to support the individuals that they provide care for to engage in behaviour changes. Therefore, it is possible that carers' motivation will have a bearing on the effectiveness of lifestyle behaviour change interventions.

The important role that carers can play was highlighted by Fox *et al.* (1985) who investigated the impact of parent involvement on the outcomes of a behavioural weight loss programme for individuals with intellectual disabilities. It was found that individuals whose parents were actively involved in the programme lost significantly more weight than individuals whose parents were minimally involved in the programme. Building upon the work of Fox *et al.* (1985), McCarran & Andrasik (1990) conducted a study further investigating the impact of involving parents / carers in a weight-loss programme. They explored outcomes for two groups of participants; in one group, parents / carers were actively involved, whereas, in the other group, parents / carers were minimally involved. Although they did not observe significant differences between the two groups, it was found that clinical outcomes were slightly better and weight loss was better maintained in the group for whom there was involvement from parents / carers. Taken together, the results of these studies highlight the key role that carers have in supporting individuals with intellectual disabilities to engage in behaviour change interventions.

Thomas & Kerr (2011) conducted a study investigating the long-term outcomes for individuals with intellectual disabilities following participation in a health promotion programme, which aimed to increase physical activity levels in individuals with intellectual disabilities. 69% of the sample of individuals with intellectual disabilities in this study was overweight / obese. Although individuals with intellectual disabilities and their carers initially appeared keen to participate in the programme, rates of non-attendance at follow-up clinics were high (21% at one year follow up; 34% at two year follow up). Carers in this study were asked to indicate what they perceived to be the barriers to access for the individuals that they provided support for, and not wanting to disrupt the client's day was cited as one of the main reasons for non-attendance. This suggests that carers may not recognise the importance of lifestyle behaviour change interventions. Moreover, the findings of this study suggest that carers' attributions might pose a barrier to supporting engagement in interventions.

Thus, carers have a vital role to play in supporting adults with intellectual disabilities to make healthy lifestyle choices. The literature suggests that carer motivation and attributions might impact upon their ability to support lifestyle behaviour change.

Motivation

Motivation for health behaviour change has been the focus of much research and many researchers have sought to develop models to understand the

process of health behaviour change. One such model, the Transtheoretical Model (Prochaska & DiClemente, 1983; Prochaska *et al.*, 1992; Prochaska & Velicer, 1997), is perhaps the most dominant in the field of motivation. The Transtheoretical Model comprises five stages, which it is proposed that an individual will go through when implementing a behaviour change. The stages incorporated within this model are:

- Precontemplation (not ready) – individuals in this stage may be unaware of the impact of their behaviour choices and are not intending to engage in behaviour change in the foreseeable future.
- Contemplation (getting ready) – in this stage, an individual may be beginning to recognise the problems associated with a behaviour and may be starting to consider behaviour change.
- Preparation (ready) – an individual in this stage may be intending to make changes to behaviour and may have begun taking steps towards behaviour change.
- Action – at this stage, individuals will have made changes to their behaviours, with the goal being to modify problem behaviours and engage in alternative healthy behaviours.
- Maintenance – individuals in this stage will have been successful in implementing behaviour change and will be working on maintaining changes and preventing relapse.

Associated with each stage are strategies, or processes of change, to facilitate the individual in progressing through the stages. Thus, the Transtheoretical Model can help clinicians to select appropriate interventions and tailor these to the needs of the individual.

Previous research has explored the application of the Transtheoretical Model of behaviour change to physical activity (e.g. Sarkin *et al.*, 2001). Interventions informed by the model have been shown to successfully support increases in physical activity (e.g. Marcus *et al.*, 1992). There have been few studies exploring the application of the Transtheoretical Model to behaviour change interventions for adults with intellectual disabilities. However, Heller *et al.* (2004) describe the application of the Transtheoretical Model to support adults with Down syndrome to increase their physical activity levels. The positive findings observed in this study suggest that this model might be usefully applied to interventions for adults with intellectual disabilities.

No previous research has explored the impact of social support to change behaviour in relation to the Transtheoretical Model. A focus on social support is particularly pertinent for adults with intellectual disabilities who can rely on carers to support healthy lifestyle choices and behaviours.

In summary, the Transtheoretical Model has been shown to be a useful framework for understanding behaviour change in the general population. However, limited research has explored its application to behaviour change in individuals with intellectual disabilities. Moreover, it is important to consider how the role that carers have in the process of behaviour change might be incorporated within the Transtheoretical Model, as carer motivation has been identified as an important factor to consider when thinking about lifestyle behaviour change in individuals with intellectual disabilities.

Carers' attributions

Melville *et al.* (2009) conducted a study exploring the knowledge and perceptions around diet and physical activity of carers of individuals with intellectual disabilities. Carers were asked about what they perceived to be barriers to adopting healthier lifestyles for individuals with intellectual disabilities. It was found that carers were more likely to rate intrapersonal barriers, such as lack of knowledge and skills and motivation for change as important, rather than interpersonal and external barriers to change. This suggests that carers perhaps did not recognise significant interpersonal and external barriers to change for individuals with intellectual disabilities, instead perceiving the main barriers for change to be within the individual. It also provides evidence to suggest that carers' attributions might impact upon motivation to support change, and this warrants further examination.

Weiner (1980) proposed that individuals make causal attributions in order to explain behaviour. He stated that all causal attributions can be characterised across three dimensions: locus (behaviour caused by internal or external factors), stability (whether behaviour is enduring or temporary) and controllability (behaviour either under control or uncontrollable). It is proposed that these causal attributions invoke an emotional reaction in the individual, which determines subsequent behaviour. Thus it is how behaviour is causally attributed and not the behaviour itself that determines subsequent reactions.

There is limited research exploring attributions around health behaviour change in carers of individuals with intellectual disabilities. Weiner's Attribution Model (1980) has not previously been applied to the study of health behaviour change, however, it has been utilised in previous studies (e.g. Wanless & Jahoda, 2002) investigating carers' attributions around challenging behaviour in individuals with intellectual disabilities. With regard to lifestyle behaviour change in individuals with intellectual disabilities, Weiner's model would suggest that if carers view the behaviour of individuals, such as having low physical activity levels, as internal, stable and uncontrollable, this might impact upon their own motivation to facilitate change. Thus, they might be less likely to seek help and adhere to interventions.

In summary, lifestyle behaviour choices present a significant problem for many individuals with intellectual disabilities. Carers and families have a key role to

play in identifying and responding to the health needs of the individuals that they provide care for. Carers' attributions potentially have an impact upon the likelihood of them supporting the individual that they provide care for to access interventions supporting behaviour change and facilitating engagement and adherence to treatment programmes. The current study will explore carers' motivation to support change and attributions around physical activity choices in adults with intellectual disabilities. It will also examine whether carers' motivation to support change in the individuals for whom they provide care is linked to their attributions.

Most previous studies involving carers of individuals with intellectual disabilities have focused on paid carers, however, a significant number of individuals with intellectual disabilities are supported by family carers, and so this study will include both paid and family carers. Furthermore, any differences between paid and family carers will be explored, as this might be indicative of different training needs.

Aims

This study aimed to explore carers' motivation to support lifestyle behaviour change and their causal attributions about physical activity choices in adults with intellectual disabilities.

Research questions

- 1) To what extent do family carers and paid carers differ in terms of their motivation to support the individual that they provide care for to engage in lifestyle behaviour changes?
- 2) To what extent do family carers and paid carers differ in terms of their attributions about physical activity choices in adults with intellectual disabilities?
- 3) Is there a significant correlation between carers' motivation to support change and their attributions?
- 4) Is there a relationship between carer motivation and attributions and i) age of the individual that they provide care for; ii) gender of the individual that they provide care for; iii) level of intellectual disabilities of the individual that they provide care for?

Method

Design

A quantitative, between-participants questionnaire design was utilised to investigate differences in the motivation to support change and attributions of physical activity choices of family and paid carers. The relationship between motivation and attributions of carers was explored. The influence of age, gender

and level of intellectual disabilities of the individual that the carer supports were also examined in relation to carers' motivation and their attributions.

Ethical Approval

Ethical approval was granted by the Scotland A Research Ethics Committee. Site approval was granted by NHS Greater Glasgow and Clyde Research and Development department (see Appendix 10 for further details).

Participants

Participants were carers of adults with intellectual disabilities who were not involved in regular physical activity that met the government recommendations of at least 30 minutes of at least moderate activity on a minimum of five days per week at the onset of the study (both paid carers and family carers). Potential participants were identified through local authority day centres, provider organisations and Area Learning Disability Teams in NHS Greater Glasgow and Clyde.

Recruitment

This study was linked to another research project which aimed to examine whether a walking intervention can improve the physical activity levels, health and well-being of adults with intellectual disabilities. Participants in this study were adults with intellectual disabilities who were not currently involved in regular physical activity, which met the current public health recommendations. Staff working in day centres, provider organisations and

Area Learning Disability Teams in NHS Greater Glasgow and Clyde provided information about the study to individuals with intellectual disabilities and their carers. Individuals who chose to participate in the study were randomised to an active intervention group or to a waiting list control group. The carers of participants recruited to this research project were approached and invited to participate in the current study, exploring their beliefs around physical activity choices in the individual that they support. Participants were provided with information about the study, and written informed consent was sought prior to taking part (see Appendices 6 and 7 for further details).

Measures

Motivation – Making Changes Questionnaire (MCQ)

A rating scale was utilised to assess carers' motivation to support change. This was adapted from the Stages of Change Readiness and Treatment Eagerness Scale (SOCRATES; Miller & Tonigan, 1996). SOCRATES was originally designed to assess readiness for change in individuals with alcohol misuse problems. The measure provides three scale scores: Recognition, Ambivalence and Taking Steps. SOCRATES has been shown to have high levels of validity and reliability (Miller & Tonigan, 1996). A parallel 'Significant Other' scale has been developed to assess the motivation of significant others. This 'Significant Other' scale was adapted for the purposes of this study. The SOCRATES 'Significant Other' scale, like the SOCRATES, yields three scale scores (Recognition, Ambivalence and Taking Steps). Participants were asked to give

their responses using a five-point Likert scale, in line with the original SOCRATES 'Significant Other' scale.

Importance and confidence have also been identified as important predictors of readiness for change (Prochaska *et al.*, 1992). Thus, in addition to the items adapted from the SOCRATES 'Significant Other' scale, participants were asked to provide ratings of the importance of change, and their confidence in their ability to support change in the individual whom they care for. These ratings were scored on a ten-point scale, as advocated by Prochaska *et al.*, 1992.

Thus, the MCQ comprised twenty one items, which related to five domains:

- Recognition (seven items; e.g. "his / her physical activity levels are a problem").
- Ambivalence (four items; e.g. "sometimes I wonder if his / her levels of physical activity are a problem").
- Taking Steps (eight items; e.g. "I have already started to try to get him / her to make changes in their physical activity levels").
- Importance (one item; "how important would you say it is for the person that you care for to make changes to their levels of physical activity?").
- Confidence (one item; "how confident would you say you are that if the person that you care for wanted to make changes to their activity levels, they could do it?").

Scoring criteria for the MCQ are provided in Appendix 8.

Attributions – Physical Activity Choices Questionnaire

Previous research looking at carers' attributions has utilised vignette methodologies. However, research (e.g. Wanless and Jahoda, 2002) has highlighted the fact that vignettes may provide limited insight into the appraisals staff make, and ratings related to vignettes may differ significantly from ratings relating to actual events. Thus, in order to assess carers' attributions around physical activity choices, carers were asked to consider the individual that they support when completing the rating scales.

The Physical Activity Choices Questionnaire (PACQ) was adapted from Hastings' (1997) Challenging Behaviour Attributions Scale (CHABA), which was designed to explore staff attributions around challenging behaviour. The CHABA comprises items which relate to five causal models: learned behaviour; biological; emotional; physical environment and stimulation, and has been shown to have acceptable levels of reliability (Hastings, 1997).

Items that were not deemed relevant to the present study were removed (e.g. items relating to self-injury). All items from the 'learned behaviour' domain were removed as these were not deemed relevant to the present study. This left four domains: biological, emotional, physical environment and stimulation. Further details about which items from the original CHABA were included /

removed are provided in Appendix 8. Items were rated on a Likert scale from one to seven, in line with the original CHABA. A rating of four indicated neutral or no attribution, a rating of more than four represented a positive attribution and a rating of less than four represented a negative attribution.

In addition to the items adapted from the CHABA, additional questions on attributional style, in line with the work of Weiner (1980), were included to assess participants' ratings of stability, controllability, globality, intentionality and locus of control of physical activity choices. Participants were also asked to give a rating of optimism for change. Participants were required to give ratings for each of these dimensions on a seven-point Likert scale, in line with the work of Weiner (1980).

Thus, the PACQ comprised twenty five items, which related to ten domains:

- Biological (five items; e.g. "They have mobility problems").
- Emotional (five items; e.g. "They are worried about something").
- Physical environment (four items; e.g. "The house where they live is too crowded with people").
- Stimulation (five items; e.g. "They are on their own a lot").
- Internal (one item; "related to something about him / her").
- Unstable (one item; "change from day to day").

- Controllable (one item; “under his / her control”).
- Global (one item; “the same in every situation”).
- Intentional (one item; “exactly what he / she wants”).
- Optimism (one item; “do you think that the person that you support could be helped to make positive changes to his / her choices about physical activity?”).

Scoring criteria for the PACQ are provided in Appendix 8.

Demographic Information

Demographic information was collected, which included: type of carer (paid / family carer); gender of the individual whom the carer supports; age of the individual whom the carer supports; level of intellectual disabilities of the individual whom the carer supports.

Procedure

Potential participants were informed of the study both verbally and through the provision of an information sheet (see Appendix 6). Following this, if the participant indicated that they wished to participate in the study, consent was sought (see Appendix 7). Participants were then asked to complete the PACQ and the MCQ. Demographic information was also collected. Data from questionnaires was coded and stored anonymously on an encrypted laptop.

Analysis

A database for data entry was created using IBM SPSS Statistics Version 19. Descriptive statistics were computed and normality of data was assessed. As sample sizes were small and data were not normally distributed, non-parametric statistics were used. Mann-Whitney tests were used to explore differences between the ratings on the MCQ and PACQ of family and paid carers. Spearman's rho tests were used to explore the relationship between carers' ratings of motivation to support change and their attributions. Mann Whitney, Spearman's Rho and Kruskal-Wallis tests were used to explore the influence of age, gender and level of intellectual disability of the individual supported by the carer on carers' ratings of motivation to support change and attributions.

Performing multiple comparisons can give rise to significant results which might be attributed to sampling error. To allow for this, it is generally recommended that results are interpreted in light of this knowledge, e.g. using a Bonferroni correction. With a large number of comparisons, this can result in a very low 'p' value. As this was an exploratory study, with a relatively small sample, it was decided not to correct for multiple comparisons, as doing so would most likely have resulted in few, if any, significant relationships being highlighted. It was felt that it was important to acknowledge any significant relationships highlighted in the findings, however, the possible influence of multiple comparisons should be kept in mind when reading the results.

Results

Demographic Information

A total of 18 carers participated in the study. Eight were paid carers (44.4%) and ten were family carers (55.6%). The mean age of the individuals that the carers supported was 38.9 years (range = 19 – 69). Nine of the individuals that the carers supported were female (50.0%); nine were male (50.0%). Nine of the individuals that the carers supported had mild intellectual disabilities (50.0%); five had moderate intellectual disabilities (27.8%) and four had severe intellectual disabilities (22.2%).

Research Question One: Motivation to support change in family and paid carers

Frequency and percentages of carer responses to the items on the Making Changes Questionnaire are provided in Appendix 9.

Reliability of the Making Changes Questionnaire

A reliability analysis of each dimension of the MCQ was carried out using Cronbach's alpha. The dimensions analysed were recognition, ambivalence and taking steps. Levels of reliability are shown in Table 1.

{Insert Table 1 here}

The recognition dimension met the criteria for excellent internal consistency. The taking steps dimension would be regarded as having questionable internal consistency. The ambivalence dimension had a negative Cronbach's alpha value due to a negative average covariance among items in this dimension. This may

be due to the small sample size, which could have resulted in sampling error. Alternatively, it might be the case that the items in this domain do not measure the same construct and therefore may not form a useful single scale. Consequently, this dimension was subsequently excluded from further analysis.

Differences between paid and family carer motivation

Median scores for each of the dimensions measured by the Making Changes Questionnaire were calculated for paid and family carers and are provided in Table 2.

{Insert Table 2 here}

Differences between the ratings of paid carers and family carers on each of the motivation dimensions were explored utilising Mann-Whitney tests. Paid carers and family carers did not differ significantly on any of the motivation dimensions, suggesting that motivation to support change was not influenced by type of carer.

Research Question Two: Attributions of family and paid carers

Frequency and percentages of carer responses to the items on the Physical Activity Choices Questionnaire are provided in Appendix 9.

Reliability of the Physical Activity Choices Questionnaire

A reliability analysis of each dimension of the PACQ was carried out using Cronbach's alpha. The dimensions analysed were biological, emotional, physical environment and stimulation. Levels of reliability are shown in Table 3.

{Insert Table 3 here}

Generally, the acceptable level for Cronbach's alpha is defined as >0.7 . None of the dimensions of the PACQ met this criteria. A Cronbach's alpha level of 0.5 – 0.6 is generally regarded as being indicative of poor internal consistency. A Cronbach's alpha level of <0.5 is regarded as unacceptable. For this reason, the 'stimulation' domain was excluded from further analysis.

Differences between paid and family carer attributions

Mean scores for each of the attribution dimensions measured by the Physical Activity Choices Questionnaire were calculated for paid and family carers and are shown in Table 4.

{Insert Table 4 here}

Higher scores reflect positive attributions, i.e. a high score on the biological attribution dimension would indicate that a carer attributed physical activity choices to biological reasons.

Correlations within the attributional dimensions were explored using Spearman's rho correlations. The 'internal' dimension was significantly correlated with the 'controllable' and 'intentional' dimensions, indicating that carers who attributed physical activity choices to factors internal to the individual also attributed these choices to be within the individual's control, and to be intentional. 'Globality' was correlated with 'controllability', indicating that carers who believed that physical activity choices generalised across situations also believed that these choices were within the individual's control. Controllability was correlated with intentionality, which suggests that carers who attributed physical activity choices to be out with the individual's control also believed that this was unintentional. With regards to treatment optimism, there was a negative correlation between controllability and carers' ratings of optimism, indicating that those who felt that physical activity choices were within the individual's control were less optimistic about the potential for change. There was a positive correlation between globality and optimism, indicating that those who believed that physical activity choices generalised across all situations were more optimistic about the potential for change.

Differences between the scores of paid carers and family carers on each of the attribution dimensions were then explored. As the sample size for each group was relatively small, the most appropriate statistical test was Mann-Whitney. Paid carers were significantly more likely to attribute physical activity choices to biological factors than family carers ($U = 15.00$, $p = 0.03$). Family carers were

significantly more likely to be optimistic about the potential for making changes to physical activity choices than paid carers ($U = 62.50$, $p = 0.04$). There was no significant difference between paid and family carers' attributions on emotional; physical environment; internal; unstable; controllable; global or intentional domains. Thus, there was some evidence of differences between the attributions of paid carers and family carers with regards to physical activity choices.

Research question three: relationship between carers' motivation and attributions

Spearman's rho correlations were conducted to explore the relationship between carer's attributions, as measured by the Physical Activity Choices Questionnaire, and their motivation to support change, as measured by the Making Changes Questionnaire (see Table 5).

{Insert Table 5 here}

There were some significant correlations between carers' attributions and their motivation to support change. Carers who attributed physical activity choices as being internal to the individual were more likely to recognise potential problems associated with physical activity choices. In addition, attributions on the 'internal' dimension were associated with 'confidence', indicating that those who thought that physical activity choices were related to factors internal to the individual were more confident about supporting the individual to make changes to these. The attribution dimensions 'globality' and 'intentionality'

were correlated with the motivation dimension 'taking steps', which suggested that carers who attributed physical activity choices to be global and intentional were more likely to already have taken steps to support the individual to make changes to these. Treatment optimism was associated with higher ratings of confidence to support change. Overall, there is some evidence to support the fact that carers' attributions are related to their motivation to support change.

Research question four: Associations between carers' motivation and attributions and age, gender and level of intellectual disabilities of the individual that they support

A Spearman's rho correlation was used to examine the relationship between carer motivation and the age of the individual that they supported. There was a significant negative correlation between age and carers' ratings of importance ($r = -0.50$, $p = 0.03$). This suggests that carers of younger individuals were more likely to rate making changes to physical activity choices as important than carers of older individuals. Age was not significantly correlated with carers' scores on the recognition, taking steps and confidence domains of the MCQ.

{Insert Table 6 here}

Mann-Whitney tests were used to explore the impact of gender of the individual that the carer supported on carers' ratings of motivation. No significant differences were observed between the ratings of carers of male individuals and carers of female individuals on any of the domains of the MCQ.

An independent samples Kruskal-Wallis test was used to explore the relationship between the level of intellectual disabilities of the individual that the carer supported and the carers' ratings of motivation to support change. This revealed a significant relationship between level of intellectual disabilities and carer scores on the recognition domain of the MCQ ($H(2) = 7.7, p = 0.02$) and carer ratings of importance ($H(2) = 6.82, p = 0.03$). Median scores for both of these motivation domains for carers of individuals with mild, moderate and severe intellectual disabilities are shown in Table 7.

{Insert Table 7 here}

Median scores indicate that carers of individuals with mild intellectual disabilities were more likely to recognise the need for change in physical activity choices and rate this more important than carers of individuals with moderate and severe intellectual disabilities. There were no significant differences between carer scores on the taking steps and confidence domains.

Spearman's rho correlations were conducted to explore the relationship between carer's attributions, as measured by the PACQ, and the age of the individual whom they supported (see Table 8).

{Insert Table 8 here}

There were significant correlations between age of the individual supported and carers' attributions to biological factors ($r = 0.48, p = 0.04$) and physical

environment ($r = -0.50$, $p = 0.03$). Age and biological factors were positively correlated, suggesting that carers of older individuals were more likely to attribute physical activity choices to biological factors. There was a negative correlation between age and physical environment factors, suggesting that carers of younger individuals were more likely to believe that physical activity choices were influenced by environmental factors.

Mann-Whitney tests were used to explore the impact of gender of the individual that the carer supported on carers' attributions. There were significant differences between gender and attributions to biological ($U = 75.00$, $p = 0.002$) and emotional ($U = 13.00$, $p = 0.01$) factors. Median scores for both of these domains for carers of male individuals and female individuals are provided in Table 9. Median scores suggest that carers of female individuals were more likely to attribute physical activity choices to biological factors, whereas carers of male individuals were more likely to attribute physical activity choices to emotional factors.

{Insert Table 9 here}

An independent samples Kruskal-Wallis test was used to explore the relationship between the level of intellectual disabilities of the individual that the carer supported and the carers' attributions. This revealed a significant relationship between level of intellectual disabilities and carer ratings on the internal ($H(2) = 7.44$, $p = 0.02$), unstable ($H(2) = 8.18$, $p = 0.02$) and controllable

($H(2) = 10.26, p = 0.006$) domains of the PACQ. Median scores for each of these attributional domains for carers of individuals with mild, moderate and severe intellectual disabilities are shown in Table 10.

{Insert Table 10 here}

Median scores suggest that carers of individuals with mild levels of intellectual disabilities are also more likely to view physical activity choices as internal to the individual, and controllable than carers of individuals with moderate or severe levels of intellectual disabilities. Median scores suggest that there was variability in carers' ratings across the 'unstability' dimension; no clear pattern emerged indicating that carers' ratings were influenced by the level of intellectual disabilities of the individual whom they supported.

Discussion

Key findings

The findings from the MCQ suggest that paid and family carers do not differ in terms of their motivation to support change. Comparison of ratings on the MCQ and PACQ provided some evidence to suggest that carers' motivation to support change was linked to their attributions of physical activity choices in the individuals that they support. Furthermore, findings suggested that the age and level of intellectual disabilities of the individual supported by the carer were correlated with carer ratings of motivation to support change and attributions. Carers of older individuals were less likely to view changes in

physical activity as important than carers of younger individuals. Similarly, carers of individuals with moderate and severe levels of intellectual disabilities were less likely to recognise the importance of supporting increased physical activity than carers of individuals with mild levels of intellectual disabilities. These findings may indicate barriers to carers supporting change in older individuals and individuals with moderate and severe levels of intellectual disabilities.

Links to previous research

Previous research has found that age tends to be negatively correlated with activity levels in adults with intellectual disabilities (Emerson, 2005). In addition, there is some evidence that individuals with more severe levels of intellectual disabilities are more likely to be inactive than individuals with less severe levels of intellectual disabilities (Robertson *et al.*, 2000; Emerson, 2005). Thus, interventions to support individuals to increase their physical activity levels are likely to be of most benefit to older adults with intellectual disabilities and individuals with more severe intellectual disabilities. However, the findings of this study indicate that carers of older individuals and individuals with more severe intellectual disabilities were less likely to recognise the importance of supporting the individual that they provide care for to make changes to their physical activity levels, which might impact upon help-seeking behaviour, and engagement in interventions.

Previous research has found that carer attitudes can present a barrier to participation in physical activity for individuals with intellectual disabilities (Messent *et al.*, 1999; Rimmer *et al.*, 2004; Frey *et al.*, 2005). This study, which suggests that carer attributions might be linked to motivation to support change, together with previous research highlighting the fact that carer perception might present a barrier to participation in activity for individuals with intellectual disabilities, highlights the importance of being aware of the impact of carer attributions, and indicates a training need to increase carers' awareness of the importance and benefits of physical activity in individuals with intellectual disabilities.

Overall, the findings of this study indicate that carers might hold a number of misconceptions about physical activity choices in individuals with intellectual disabilities. This may, in turn, influence motivation to support change. Training sessions should be designed to reflect the importance of attributions and should aim to target such misconceptions. Previous research has shown that when carers of individuals with intellectual disabilities perceive participation in physical activity to be of benefit to the individual that they support (e.g. to decrease joint pain), the individual is more likely to be active (Heller *et al.*, 2002). This suggests that interventions aiming to modify carer attributions, where appropriate, might facilitate participation in physical activity for individuals with intellectual disabilities.

Although paid and family carers did not differ significantly in terms of their ratings of motivation to support change, the findings from the PACQ suggest that there was some evidence of differences between the attributions of paid carers and family carers with regards to physical activity choices. Paid carers appeared more likely to attribute physical activity choices to biological factors. Moreover, family carers were more likely to be optimistic about the potential for change in physical activity choices. Further research is required to explore more fully the attributions of paid and family carers in order to identify whether their training needs might differ.

Strengths and limitations

This was the first study to explore the relationship between carers' motivation to support change and their attributions. Although this was a preliminary, exploratory study, findings suggest that there is a link between carers' motivation to support change and their attributions. This warrants further investigation.

A limitation of this study was the small sample size, which may limit the generalizability of findings. In addition, it is possible that there might have been a participant bias, with the carers who volunteered to participate in this study being more mindful of the importance of physical activity and more open to supporting change in the individuals that they support.

In addition, the low levels of internal consistency observed on the PACQ dimensions and the 'Taking Steps' dimension of the MCQ is a limitation. This might be related to the small sample size and it would be useful to further explore the utility of the PACQ and MCQ with a larger sample. A further limitation associated with the measures is the fact that they were self-report, which might have resulted in response bias.

Practical Applications and Implications for Future Research

Findings indicated that carers generally recognised the importance of supporting the individuals that they provide care for to make changes to their physical activity levels, but appeared to lack confidence in their ability to support change. The low ratings of confidence to support change indicate that there may be a need for training to support carers in feeling confident in their ability to support change. This is further supported by findings indicating that carers' attributions might impact upon motivation, and training should aim to address attributions. Furthermore, there is a need for further research to explore more fully the attributions of paid and family carers in order to identify whether their training needs might differ.

While further evaluation is required, it is possible that the MCQ could be a useful tool for identifying barriers to supporting change in carers of individuals with intellectual disabilities. The dimensions of the MCQ might relate to the stages identified in the Transtheoretical Model. Higher scores on the

‘recognition’ dimension of the MCQ might indicate that an individual is at a ‘contemplation’ / ‘preparation’ stage, whereas low scores on this dimension might indicate that an individual is at a ‘precontemplation’ stage. Higher scores on the ‘taking steps’ dimension might indicate that an individual is at a ‘preparation’ / ‘action’ stage. As there are a number of processes of change associated with each stage of the Transtheoretical Model, this might allow clinicians to tailor interventions for individuals according to their stage of change. Further research is required to further explore the utility of the MCQ, and examine whether it is predictive of outcomes in intervention studies.

Conclusions

Carers’ attributions appear to be linked to their motivation to support change. This is particularly marked in carers of older individuals and individuals with more severe levels of intellectual disabilities. As such individuals are most likely to benefit from interventions to support them to increase their activity levels, it is important that further research is conducted into the best way to support carers in facilitating change in the individuals that they support. This was an initial, exploratory study, and therefore, the generalizability of the findings is somewhat limited. Nonetheless, this study has shown that this is a valid area for future research.

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Table 1: Cronbach's alpha values for dimensions of the MCQ

Dimension	Alpha
Recognition	0.95
Ambivalence	-1.43
Taking Steps	0.60

Table 2: Median scores and interquartiles of paid and family carers for each dimension on the MCQ, with Mann-Whitney test results

Dimension	Paid carers	Family carers	U	p
Recognition	23.00 (9)	25.50 (13)	45.50	0.62
Taking Steps	24.00 (5)	24.00 (5)	47.50	0.50
Importance	6.50 (3)	8.00 (4)	51.00	0.32
Confidence	3.00 (4)	5.50 (4)	58.00	0.11

Table 3: Cronbach's alpha values for dimensions of the PACQ

Dimension	Alpha
Biological	0.56
Emotional	0.63
Physical environment	0.54
Stimulation	0.35

Table 4: Median scores and interquartiles of paid and family carers for each attribution dimension on the PACQ, with Mann-Whitney test results

Attribution dimension	Paid carer	Family carer	U	p
Biological	17.50 (4)	14.00 (3)	15.00*	0.03
Emotional	16.00 (3)	17.00 (3)	50.00	0.36
Physical Environment	11.00 (2)	12.50 (6)	52.00	0.28
Internal	5.00 (3)	5.00 (1)	41.50	0.90
Unstable	4.00 (1)	3.50 (1)	38.00	0.85
Controllable	4.50 (2)	5.00 (2)	43.50	0.74
Global	4.00 (0)	4.00 (1)	32.50	0.36
Intentional	4.50 (2)	3.50 (2)	26.50	0.22
Optimism	4.00 (3)	5.50 (2)	62.50*	0.04

*. Significant at the 0.05 level.

Table 5: Spearman's Rho Correlations Between Carers' Attributions and Motivation to Support Change

		Internal	Unstable	Controllable	Global	Intentional	Optimism	Recognition	Taking steps	Importance	Confidence
Internal	Correlation Coefficient	1.000	.147	.743**	.325	.570*	-.371	.473*	-.171	.324	-.547*
	Sig. (2-tailed)	.	.562	.000	.188	.014	.129	.047	.498	.190	.019
Unstable	Correlation Coefficient	.147	1.000	.332	-.065	.016	-.462	.236	.156	.234	-.265
	Sig. (2-tailed)	.562	.	.178	.798	.951	.054	.345	.535	.351	.288
Controllable	Correlation Coefficient	.743**	.332	1.000	.531*	.481*	-.479*	.366	-.134	.292	-.209
	Sig. (2-tailed)	.000	.178	.	.023	.043	.044	.135	.597	.240	.405
Global	Correlation Coefficient	.325	-.065	.531*	1.000	.383	-.596**	.134	-.496*	-.082	-.147
	Sig. (2-tailed)	.188	.798	.023	.	.117	.009	.595	.036	.747	.561
Intentional	Correlation Coefficient	.570*	.016	.481*	.383	1.000	-.279	.165	-.535*	-.020	-.307
	Sig. (2-tailed)	.014	.951	.043	.117	.	.262	.512	.022	.937	.215
Optimism	Correlation Coefficient	-.371	-.462	-.479*	-.596**	-.279	1.000	-.313	.153	-.119	.601**
	Sig. (2-tailed)	.129	.054	.044	.009	.262	.	.206	.544	.639	.008
Recognition	Correlation Coefficient	.473*	.236	.366	.134	.165	-.313	1.000	-.171	.882**	-.677**
	Sig. (2-tailed)	.047	.345	.135	.595	.512	.206	.	.499	.000	.002
Ambivalence	Correlation Coefficient	-.066	-.002	.188	-.036	-.141	.008	.479*	.183	.530*	-.021
	Sig. (2-tailed)	.794	.993	.455	.888	.577	.976	.044	.467	.024	.935
Taking steps	Correlation Coefficient	-.171	.156	-.134	-.496*	-.535*	.153	-.171	1.000	.039	.260
	Sig. (2-tailed)	.498	.535	.597	.036	.022	.544	.499	.	.878	.297
Importance	Correlation Coefficient	.324	.234	.292	-.082	-.020	-.119	.882**	.039	1.000	-.521*
	Sig. (2-tailed)	.190	.351	.240	.747	.937	.639	.000	.878	.	.027
Confidence	Correlation Coefficient	-.547*	-.265	-.209	-.147	-.307	.601**	-.677**	.260	-.521*	1.000
	Sig. (2-tailed)	.019	.288	.405	.561	.215	.008	.002	.297	.027	.

*. Correlation is significant at the 0.05 level. **. Correlation is significant at the 0.01 level.

Table 6: Spearman's rho correlation between carer motivation and age of the individual that they support

		Recognition	Taking Steps	Importance	Confidence
Age of individual with ID	Correlation Coefficient	-0.41	0.06	-0.50*	0.01
	Sig. (2-tailed)	0.09	0.82	0.03	0.96

*. Correlation is significant at the 0.05 level.

**. Correlation is significant at the 0.01 level.

Table 7: Median scores and interquartiles on motivation domains by level of intellectual disabilities of individual supported, with results of Kruskal-Wallis test

		Level of ID of individual supported by carer			Kruskal-Wallis results		
		Mild (n = 9)	Moderate (n = 5)	Severe (n = 4)	H	df	p
Motivation dimension	Recognition	29.00 (5)	18.00 (8)	20.50 (7)	7.75*	2	0.02
	Taking Steps	24.00 (3)	27.00 (7)	24.00 (11)	1.86	2	0.40
	Importance	9.00 (3)	6.00 (4)	6.50 (3)	6.82*	2	0.03
	Confidence	3.00 (5)	7.00 (3)	3.50 (6)	4.43	2	0.11

*. Significant at the 0.05 level.

Table 8: Spearman's rho correlation between carer attributions and age of the individual that they support

		Biological	Emotional	Physical environment	Internal	Unstable	Controllable	Global	Intentional	Optimism
Age of individual with ID	Correlation Coefficient	.482*	-.446	-.504*	-.258	-.209	-.363	.120	.020	-.157
	Sig. (2-tailed)	.043	.064	.033	.301	.405	.139	.634	.939	.535

*. Correlation is significant at the 0.05 level.

**. Correlation is significant at the 0.01 level.

Table 9: Median scores and interquartiles on biological and emotional attribution domains by gender of individual supported, with Mann-Whitney test results

		Gender of individual supported by carer		Mann-Whitney results	
		Male (n = 9)	Female (n = 9)	U	P
Attribution dimension	Biological	13.00 (3)	17.00 (4)	75.00**	0.002
	Emotional	19.00 (3)	16.00 (2)	13.00**	0.01
	Physical Environment	12.00 (5)	10.00 (3)	19.50	0.06
	Internal	5.00 (2)	5.00 (3)	29.50	0.31
	Unstable	4.00 (2)	4.00 (2)	34.50	0.58
	Controllable	5.00 (1)	4.00 (3)	24.00	0.12
	Global	4.00 (0)	4.00 (1)	33.00	0.36
	Intentional	4.00 (2)	3.00 (3)	41.50	0.93
	Optimism	4.00 (4)	5.00 (2)	50.00	0.39

** . Significant at the 0.01 level

Table 10: Median scores and interquartiles on internal, unstable and controllable attribution domains by level of intellectual disabilities of individual supported, with Kruskal-Wallis test results

		Level of intellectual disabilities of individual supported by carer			Kruskal-Wallis test results		
		Mild (n = 9)	Moderate (n = 5)	Severe (n = 4)	H	df	p
Attribution dimension	Biological	14.00 (5)	15.00 (7)	17.50 (4)	2.57	2	0.28
	Emotional	17.00 (3)	16.00 (6)	14.50 (4)	4.86	2	0.09
	Physical environment	12.00 (5)	10.00 (5)	11.00 (5)	1.57	2	0.46
	Internal	6.00 (1)	4.00 (3)	4.00 (3)	7.44*	2	0.02
	Unstable	4.00 (2)	4.00 (3)	4.00 (2)	8.18*	2	0.02
	Controllable	5.00 (1)	3.00 (3)	4.00 (2)	10.26**	2	0.006
	Global	4.00 (0)	3.00 (2)	4.00 (0)	5.82	2	0.06
	Intentional	4.00 (2)	2.00 (2)	4.00 (3)	5.36	2	0.07
	Optimism	4.00 (4)	5.00 (2)	4.50 (2)	4.42	2	0.11

*. Significant at the 0.05 level

**. Significant at the 0.01 level

Changing Times,
Changing Expectations:
A Reflective Account

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Abstract

This reflective account is based on my experiences of working in a specialist placement within a Cardiac Rehabilitation Clinical Psychology service. I draw upon Gibbs' (1988) model of reflection as a framework to structure my thoughts and reflections. In this account, I explore my learning about the impact of government policy on Clinical Psychology practice, and on the wider context of service provision. This is a time of change for the profession of Clinical Psychology and I reflect upon the differences between what I anticipated when initially considering a career in Clinical Psychology and the realities of what I now face as I consider my future career. I reflect on how the role of the Clinical Psychologist has changed in accordance with the increased focus on increasing access to psychological therapies. I explore what these changes mean in terms of the roles that Clinical Psychologists may be expected to adopt. I also reflect on the challenges and benefits of working within a multidisciplinary team, and on the importance of understanding my role as an individual within a team.

Designed by Descartes?

A Reflective Account

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Abstract

This reflective account is based on my experiences of working in a specialist placement within a Weight Management service. I draw upon Rolfe *et al.*'s (2001) framework for reflexive practice in structuring my reflections. In this account, I reflect upon some key experiences over the course of my placement, which have made me question whether physical and mental health services are really quite separate and distinct. I reflect on the implications of this. Recent government policy has highlighted the importance of close working alliances between different professionals; however, I consider whether these policies are being met in practice. I go on to consider how Clinical Health Psychologists can occupy quite a unique role, spanning physical and mental health settings. I reflect on how the skills of Clinical Psychologists can be applied in overcoming the physical / mental health divide and facilitating closer working relationships between staff in both fields.

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- Castonguay TW, Dallman MF, Stern JS. Some metabolic and behavioural effects of adrenalectomy in obese Zucker rats. *Am J Physiol* 1986; **251**: R923-R933.
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- Maher VMG, Thompson GR. Analysis of evidence from cholesterol-lowering and regression trials. *J Drug Dev Suppl* 1990; **3/1**: 199-203.

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- Lissner L, Bengtsson C, Lapidus L. Body weight variability and mortality in the Gothenburg Prospective Studies on men and women. In: Bjorntorp P, Rossner S (eds). *Obesity in Europe 88: Proceedings of the First European Congress on Obesity*. Libbey: London, 1989, pp 55-60.
- Paul AA, Southgate DAT (eds) *McCance and Widdowson's The composition of foods*. 4th edn. HMSO: London, 1978.

- National Research Council. *Diet and health*, National Academy Press: Washington DC 1989.

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Type each table on a separate page; number tables consecutively and supply a brief title for each. Each table should have a caption. Cite each table in the text in consecutive order, using Arabic numbers.

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APPENDIX 2: SEARCH STRATEGY

intellectual disability, intellectual difficulty, intellectual retardation, learning disability, learning difficulties, learning disorders, mental handicap, mental retardation, mental disability, developmental disabilities, special needs.

(intellectual disab* OR intellectual diff* OR intellectual retard* OR learning disab* OR learning difficult* OR learning disorder* OR mental* handicap* OR mental* retard* OR mental* disab* OR developmental disabilit* OR special need*)

obesity, obese, overweight.

(obes* OR overweight*)

weight, weight gain, weight loss, weight reduction, body mass index, diet, dietary intake, calorie intake, nutrition, food, eating behaviour, exercise, physical activity, inactivity, fitness, physical therapy, walking; health promotion, health education, intervention, programme, therapy.

(weight gain OR weight los* OR weight reduc* OR body mass index OR BMI OR diet* OR calorie intake OR nutrition OR food OR eat* OR exercis* OR physical activ* OR inactiv* OR fitness OR physical therapy OR walking OR health promotion OR health education OR interven* OR programme OR therap*)

APPENDIX 3: TABLE OF EXCLUDED STUDIES

Study	Reason for exclusion
Harris & Bloom (1984)	Unclear if participants in study were overweight / obese
Podgorski et al. (2004)	Unclear if participants in study were overweight / obese
Rimmer et al. (2004)	Study included participants of normal weight
Aronow & Hahn (2005)	Not an intervention study
Chapman et al. (2005)	Study included participants of normal weight
Yamaki (2005)	Not an intervention study
Bertoli et al. (2008)	Study included participants of normal weight
Chapman et al. (2008)	Study included participants of normal weight
Hall & Thomas (2008)	Not an intervention study
Poynor (2008)	Did not include a measure of weight loss
Bazzano et al. (2009)	Study included participants of normal weight
Moss (2009)	Study included participants of normal weight
Biswas et al. (2010)	Not an intervention study
Wu et al. (2010)	Study included participants of normal weight
Calders et al. (2011)	Study included participants of normal weight
Johnson et al. (2011)	Not an intervention study
Singh et al. (2011)	Case study
Thomas & Kerr (2011)	Study included participants of normal weight

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- Singh NN, Lancioni GE, Singh ANA, Winton ASW, Singh ADA, Singh J (2011) A Mindfulness-Based Health Wellness Program for Individuals With Prader-Willi Syndrome. *Journal of Mental Health Research in Intellectual Disabilities*, 4, 90 – 106
- Thomas GR, Kerr MP (2011) Longitudinal Follow-up of Weight Change in the Context of a Community-Based Health Promotion for Adults with an Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*, 24 (4), 381 – 387

APPENDIX 4: METHODOLOGICAL QUALITY RATING SCALE

Study ID (Author, year):

1. **The study addresses an appropriate and clearly focused question?**
Well covered ☐ 3 Poorly addressed ☐ 1
Adequately addressed ☐ 2 Not addressed ☐ 0

2. **What study design was utilised?**
Randomised controlled trial ☐ 5
Non-randomised controlled trial ☐ 4
Cohort study ☐ 3
Case-controlled study ☐ 3
Before-after study ☐ 2
Non-comparative (e.g. case study) ☐ 1

3. **How was Learning Disability assessed?**
Validated measure confirmed by researcher ☐ 2
Not addressed ☐ 0

4. **Generally accepted diagnostic criteria were used to confirm diagnosis of obesity (e.g. BMI \geq 25-30 kg/m²; waist measurement; waist-to-hip ratio).**
Yes ☐ 2
No ☐ 0

Study Participants

5. **The cases and controls were taken from comparable populations.**
Yes ☐ 2
No ☐ 0

6. **The characteristics of the participants and controls included in the study were clearly described to allow adequate comparisons to be made.**
Well covered ☐ 3 Poorly addressed ☐ 1
Adequately addressed ☐ 2 Not addressed ☐ 0

7. **Cases were clearly defined and differentiated from controls.**
Yes ☐ 2
No ☐ 0

8. **Inclusion and exclusion criteria were clearly specified and were appropriate to test study hypotheses.**
Yes ☐ 2
No ☐ 0

9. **The same exclusion criteria were used for both cases and controls.**
Yes ☐ 2
No ☐ 0

10. The study indicated how many of the people who were asked to take part did so in each of the groups being studied.

Yes ☐ 2

No ☐ 0

11. What is the sample size? (For both cases and controls)

Sample size is greater than 27 in each therapy group or a description of how sample size was determined (i.e. an adequate Power calculation) is provided. ☐ 2

Sample size less than 27 in each group or there is no adequate Power calculation ☐ 1

Not addressed ☐ 0

Study Design

12. A description of the methodology used is included?

Well covered ☐ 3 Poorly addressed ☐ 1

Adequately addressed ☐ 2 Not addressed ☐ 0

13. Study design is appropriate to test the hypotheses.

Yes ☐ 2

No ☐ 0

14. The assignment of participants to treatment groups is randomised.

Yes ☐ 2

No ☐ 0

15. Precise details of the interventions intended for each group are provided along with a description of how, by whom and when they were actually administered.

Well covered ☐ 3 Poorly addressed ☐ 1

Adequately addressed ☐ 2 Not addressed ☐ 0

16. Details of how the interventions were standardized are provided (i.e. manualised treatment, standard length of treatments)

Yes ☐ 2

No ☐ 0

17. Details of how the adherence of care providers / participants with the protocol was assessed/ enhanced are provided.

Well covered ☐ 3 Poorly addressed ☐ 1

Adequately addressed ☐ 2 Not addressed ☐ 0

Results

18. The outcomes are clearly defined.

Yes ☐ 2

No ☐ 0

19. All relevant outcomes are measured in a standard, valid and reliable way.

Yes ☐ 2

No ☐ 0

20. The assessment of outcome is made blind to exposure status.

Yes ☐ 2

No ☐ 0

21. Has a summary of results for each group and controls been included (i.e. means, SDs, p-values, confidence intervals), plus estimated effect sizes?

Effect size, plus summary statistics ☐ 2

Summary statistics only ☐ 1

No ☐ 0

22. Where the study is carried out at more than one site, results are comparable for all sites.

Yes ☐ 2

No ☐ 0

23. The main potential confounders are identified and taken into account in the design and analysis.

Well covered ☐ 3

Poorly addressed ☐ 1

Adequately addressed ☐ 2

Not addressed ☐ 0

Overall assessment of the study

24. How well have the researchers tried to minimise the risk of bias of confounding variables?

++ ☐ 2

+ ☐ 1

- ☐ 0

25. Taking into account clinical considerations, your evaluation of the methodology used, and the statistical power of the study, are you certain that the overall effect is due to the study intervention?

Yes, definitely ☐ 3

Possibly, somewhat sure ☐ 1

Yes, fairly sure ☐ 2

No, not sure ☐ 0

TOTAL SCORE = ____/ 60

Overall study rating

A (46 - 60) ☐

B (31 - 46) ☐

C (16 - 30) ☐

D (0 - 15) ☐

APPENDIX 5: JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES AUTHOR GUIDELINES

Journal of Applied Research in Intellectual Disabilities

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Author Guidelines

1. GENERAL

The *Journal of Applied Research in Intellectual Disabilities* is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

2.1 Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship.

It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

Acknowledgements: Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study and any potential conflict of interest if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

2.2 Ethical Approvals

Research involving human participants will only be published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 www.wma.net) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant (or the participant's representative, if they lack capacity), and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included.

All studies using human participants should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.

Ethics of investigation: Papers not in agreement with the guidelines of the Helsinki Declaration as revised in 1975 will not be accepted for publication.

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Clinical trials should be reported using the CONSORT guidelines available at www.consort-statement.org. A CONSORT checklist should also be included in the submission material (www.consort-statement.org).

The *Journal of Applied Research in Intellectual Disabilities* encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public trials registries: www.clinicaltrials.org, www.isrctn.org. The clinical trial registration number and name of the trial register will then be published with the paper.

2.4 Conflict of Interest and Source of Funding

Conflict of Interest: Authors are required to disclose any possible conflict of interest. These include financial (for example patent ownership, stock ownership, consultancies, speaker's fee). Author's conflict of interest (or information specifying the absence of conflict of interest) will be published under a separate heading.

The *Journal of Applied Research in Intellectual Disabilities* requires that sources of institutional, private and corporate financial support for the work within the manuscript must be fully acknowledged, and any potential conflict of interest noted. As of 1st March 2007, this information is a requirement for all manuscripts submitted to the journal and will be published in a highlighted box on the title page of the article. Please include this information under the separate headings of 'Source of Funding' and 'Conflict of Interest' at the end of the manuscript.

If the author does not include a conflict of interest statement in the manuscript, then the following statement will be included by default: 'No conflict of interest has been declared'.

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4. SUBMISSION OF MANUSCRIPTS

Submissions are now made online using ScholarOne Manuscripts (formerly Manuscript Central). To submit to the journal go to <http://mc.manuscriptcentral.com/jarid>. If this is the first time you have used the system you will be asked to register by clicking on 'create an account'. Full instructions on making your submission

are provided. You should receive an acknowledgement within a few minutes. Thereafter, the system will keep you informed of the process of your submission through refereeing, any revisions that are required and a final decision.

4.1 Manuscript Files Accepted

Manuscripts should be uploaded as Word (.doc) or Rich Text Format (.rft) files (not write-protected) plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing.

4.2 Blinded Review

All articles submitted to the journal are assessed by at least two anonymous reviewers with expertise in that field. The Editors reserve the right to edit any contribution to ensure that it conforms with the requirements of the journal.

5. MANUSCRIPT TYPES ACCEPTED

Original Articles, Review Articles, Brief Reports, Book Reviews and **Letters to the Editor** are accepted. **Theoretical Papers** are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

6. MANUSCRIPT FORMAT AND STRUCTURE

6.1 Format

Language: The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

6.2 Structure

All manuscripts submitted to the *Journal of Applied Research in Intellectual Disabilities* should include:

Cover Page: A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.

Running Title: A short title of not more than fifty characters, including spaces, should be provided.

Keywords: Up to six key words to aid indexing should also be provided.

Main Text: All papers should be divided into a structured abstract (150 words) and the main text with appropriate sub headings. A structured abstract should be given at the beginning of each article, incorporating the following headings: Background, Materials and Methods, Results, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study. The text should then proceed through sections of Introduction, Materials and Methods, Results and Discussion, and finally Tables. Figures should be submitted as a separate file.

Style: Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:

- Include all figure legends, and tables with their legends if available.
- Do not use the carriage return (enter) at the end of lines within a paragraph.
- Turn the hyphenation option off.
- In the cover email, specify any special characters used to represent non-keyboard characters.
- Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).
- Use a tab, not spaces, to separate data points in tables.
- If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

6.3 References

The reference list should be in alphabetic order thus:

-Emerson E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*. Cambridge University Press, Cambridge.

-McGill P. & Toogood A. (1993) Organising community placements. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services* (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.

-Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. *Mental Handicap Research* 5, 130-145

Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al.* 1977). Authors are responsible for the accuracy of their references.

6.4 Tables, Figures and Figure Legends

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.

Figures should be referred to in the text as Figures using Arabic numbers, e.g. Fig.1, Fig.2 etc, in order of appearance. Figures should be clearly labelled with the name of the first author, and the appropriate number. Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

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7. AFTER ACCEPTANCE

Upon acceptance of a paper for publication, the manuscript will be forwarded to the Production Editor who is responsible for the production of the journal.

7.1 Proof Corrections

The corresponding author will receive an e-mail alert containing a link to a website. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF file from this site.

Proofs must be returned to the Production Editor within 3 days of receipt.

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WALKING AND LEARNING DISABILITIES

Carer Information Sheet

We would like to invite the person with learning disabilities whom you support to take part in a research study. Please keep this information sheet. Before the person you support decides it is important to understand why the research is being done and what it will involve. You may be able to help the person you support decide whether they want to take part. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Thank you for reading this.

What will the research study find out?

The aim of this study is to encourage adults with learning disabilities to increase their walking. A member of our research team, Professor Mutrie, has shown that this approach works for adults who do not have learning disabilities. This is the first study to use this approach with adults who have learning disabilities.

People who are regularly active have been shown to feel better, sleep better, have more energy, control weight and have a lower risk of developing certain diseases (heart disease, cancer, bone diseases and diabetes). Walking is a great way to be active as you don't need any special equipment, clothes or facilities and there is very little risk. The person you support will not be asked to change any aspects of their diet. Our goal is to help the person you support gradually increase how much walking they do. The kind of walking we suggest is walking further to the bus stop, walking with a friend or carer, or walking for leisure at the weekend.

Why do you want the person I support to take part?

The person with learning disabilities whom you support has been invited to take part in the study because he/she is using the learning disabilities services. We would like 100 individuals who want to be more active to take part. We will look at whether this approach helps the person you support do more walking over a six month period.

What will the study involve?

If the person you support wants to find out more about the study a researcher can contact them to arrange a time to meet. This meeting would be to discuss the study, and answer any questions about the study. If the person you support does not want to meet the researcher, please let us know. Some people with learning disabilities are unable to consent to participation in research. If this is the case, under the procedures of the Adults with Incapacity (Scotland) Act a relative, or welfare guardian can be asked to consider providing consent to participation.

If the person chooses to meet the researcher, they will explain the study to the person you support, and answer any questions. The person with learning disabilities you support will be invited to choose whether to take part in the study. The person you support will be given a copy of the consent form to keep. The person you support does not have to take part in the study it is OK to say 'no' and this will not affect the care that the person you support receives from learning disabilities services.

If the person you support chooses to take part in the study, they would be involved in the study for about six months. The researcher would like to arrange three meetings, over the six months. Each meeting will last about one hour. If this seems too long, the person can choose shorter meetings. At each meeting, the researcher would like to ask questions about the life of the person you support, including things they enjoy doing, questions about their health and the support they receive, and questions about how much activity they do. The researcher will also ask to measure the person's weight, height and waist circumference. The person you support will be asked to wear a special belt each day for one week at the beginning, middle and end of the study. It measures how active people are.

The researcher will also ask for specific consent to speak to carers about the person with learning disabilities activities and the support they receive.

After the first meeting with the researcher a walking coordinator will arrange to meet the person you support to talk about the walking program.

What does the walking program involve?

The walking coordinator will arrange to meet the person you support three times over a 12 week period. These sessions are to help the person find ways to do more walking. The walking coordinator will work with the person you support to design a walking program that suits the person you support. Participants will choose how to do more walking. If the person wants a carer can be involved in these sessions.

After the walking program is finished, we will invite the person you support to tell us what they think about the walking program. It would be useful if carers can also tell us your thoughts on the walking program. We are interested to find out if the walking program helps people change their physical activity levels and think about how to improve the walking program for future use.

If the person you support is harmed by taking part in this research project, there are no special compensation arrangements. If they are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this if you, or the person you support, wish to complain about any aspect of the way you have been treated during the course of this study, the normal National Health Service complaints mechanism will be available.

What is the role of carers in the study?

If the person with learning disabilities decides to take part they will be invited to choose if they want carers to support them. The carers could be asked to support the

person with learning disabilities during the research interviews, and during the three sessions with the walking coordinator. Family carers and paid carers can be involved in supporting the person.

There are some questionnaires for carers to complete. These ask the carer their views on physical activity and questions about what activities the person with learning disabilities does at home, and in the community.

During the six month period the carers will be invited to support the person with learning disabilities to gradually do more walking. As well as giving general support to the person with learning disabilities, the carers will be asked to help them answer the questions, make a note of activities and make choices about how to be more active.

Will taking part in the study help me, or the person I support?

If the person you support decides to take part, they may benefit from doing more walking. Other studies have found that walking more helps people feel better. However, there is no guarantee the walking program will help the person you support do more walking. We want to find out if the walking program works.

What will happen if the person I support decides not to take part in the study?

The person with learning disabilities whom you support does not have to take part in this research study. It is OK to say 'no'. If he/she decides not to take part in the study this will not affect the care that the person you support receives from anybody who provides care or support to that person.

What if the person I support changes his/her mind about taking part during the study?

The person you support can change his/her mind about taking part, or stop, at any time. He/she does not have to give a reason for changing their mind. If he/she changes their mind about taking part in the study this will not affect the care the person you support receives from the services.

Where will the sessions take place?

The researcher, and walking coordinator, will arrange to meet with the person with learning disabilities at a place that is convenient for them. He/she can choose where they want to meet with the researcher, and walking coordinator. The researcher, and walking coordinator, could meet at the home of the person you support. If this is not suitable, the researcher, and walking coordinator, will arrange to meet somewhere that is suitable for the person you support. The person you support will be invited to choose if they would like someone to support them during the interviews.

What will happen to the information the research team collect?

The research team will keep all the information provided in strict confidence. No one outside of the research team will have access to the information provided. The information will be kept very safely on a computer database. The Data Protection Act will be adhered to at all times.

Who is organising and funding the research?

This research study is organised by researchers at the University of Glasgow and Strathclyde University. The research team have organised other studies that adults with learning disabilities have participated in. The money to pay for the study was provided by the Chief Scientist's Office, of the Scottish Government.

Has ethical approval been granted for this study?

This study has been granted ethical approval by the Scotland A Research Ethics Committee, and a local Research Ethics Committee for NHS Greater Glasgow and Clyde.

When will the study take place?

This study will take place in 2012-2014 but the involvement of the person you support will only be for six months.

What will happen to the results of the study?

After the study is finished, we will post out information about the findings of this research study to everyone who takes part. Findings of this study will also be given to managers of learning disabilities health and social work services. The research findings will be written into reports which will be published. It will not be possible to identify any of the individuals who take part in the study from the reports, as all the information will be anonymised, with information from many individuals grouped together.

How can I find out more about this study?

If you would like to discuss any aspect of this study, or wish to ask any questions please ask the researcher, or contact members of the research team, at any stage of the study.

If you want to talk to someone independent of the research study please contact Professor Andrew Jahoda (Telephone: 0141 211 3878). Professor Jahoda will try and answer any questions you have about the study.

Thank you for taking the time to read this information sheet.



WALKING AND LEARNING DISABILITIES

CARER CONSENT FORM

This form asks if I will support the person named below to take part in a research study of a walking intervention. I know that I am not providing consent for the person with learning disabilities I support to take part in the study.

Name of participant.....

I am completing this form as the carer that the participant has chosen to support them during the walking study. Other carers will also support the individual.

My relationship to the participant is (please tick):

family carer ☐

paid carer ☐

other, please specify.....

I know that I am not a participant in the study so I will not be asked for information about my own lifestyle, or invited to increase my physical activity levels.

A researcher will ask me questions about the health and lifestyle of the person I support. I know I will be asked questions about my views about the activities of the person I support. I will be asked to support the participant to collect information about their physical activity. I will also be involved in supporting the participant to try and do more walking.

The researchers will keep all the information confidential. Only members of the research team will have access to the information I discuss.

I understand that participation in the research study might help the person with learning disabilities I support.

Please initial the box to show you agree with each statement

I have been given an information sheet about the study

☐

YES

I have asked all the questions I want to

☐

YES

I am satisfied that my questions have been thoroughly answered

☐

YES

I know it is OK to say 'no' to supporting the person to take part in the study.

☐

I don't have to take part. I don't have to say why.

YES

If I say 'no', I know it will not affect the future health care, or support, that the person

☐

I support receives

YES

I know the research team will write about the study results. However, the results will
not include my name, or the name of the person I support.

☐

No one will be able to identify me, or the person with learning disabilities

I support, from the results.

YES

I agree to supporting the person I support to take part in the research study

☐

YES

Signed

Name

Date



MAKING CHANGES- CARER QUESTIONNAIRE

In this questionnaire, we would like you to think about the physical activity choices of the person that you support. Physical activity choices include things like going out for a walk, helping with the housework and going to the gym.

INSTRUCTIONS: Please read the following statements carefully. Each one describes a way that you might (or might not) feel about the physical activity choices of the person that you support. For each statement, circle one number from 1 to 5, to indicate how much you agree or disagree with it right now. Please circle one number for each statement.

	NO! Strongly disagree	No Disagree	? Undecided or unsure	Yes Agree	YES! Strongly agree
1. I really want the person that I support to make changes to their physical activity.	1	2	3	4	5
2. Sometimes I wonder if his / her levels of physical activity are a problem.	1	2	3	4	5
3. If he / she does not make changes to their activity levels soon, their health is going to get worse.	1	2	3	4	5
4. I have already started to try to get him / her to make changes in their physical activity levels.	1	2	3	4	5
5. His / her activity levels were a problem at one time, but they have managed to make changes.	1	2	3	4	5
6. Sometimes I wonder if his / her activity levels are negatively affecting other people.	1	2	3	4	5
7. His / her physical activity levels are a problem.	1	2	3	4	5
8. I'm not just thinking about helping the person I support to make changes to their activity levels, I'm already doing something about it.	1	2	3	4	5
9. The person I support has already made changes to their activities and needs to find ways to stop from slipping back into their old pattern.	1	2	3	4	5
10. He / she has serious problems related to their levels of activity.	1	2	3	4	5

Scoring Criteria for the Making Changes Questionnaire
--

- Items 1, 3, 7, 10, 12, 15, 17 are summed to obtain the “Recognition” subscale (possible range = 7 – 35).
- Items 2, 6, 11, 16 are summed to obtain the “Ambivalence” subscale (possible range = 4 – 20).
- Items 4, 5, 8, 9, 13, 14, 18, 19 are summed to obtain a “Taking Steps” subscale (possible range = 8 – 40).

**Physical Activity Choices Questionnaire – Items included from
original CHABA (Hastings, 1997)**

Original CHABA item	Domain	Included
They are given things to do that are too difficult for them	Learned behaviour	No
They are physically ill	Biological	Yes
They do not like bright lights	Physical environment	No
They are tired	Biological	Yes
They cannot cope with high levels of stress	Emotional	Yes
Their house / classroom is too crowded with people	Physical environment	Yes
They are bored	Stimulation	Yes
Of the medication that they are given	Biological	Yes
They are unhappy	Emotional	Yes
They have not got something that they wanted	Learned behaviour	No
They live in unpleasant surroundings	Physical environment	Yes
They enjoy it	Stimulation	Yes
They are in a bad mood	Emotional	No
High humidity makes them uncomfortable	Physical environment	No
They are worried about something	Emotional	Yes
Of some biological process in their body	Biological	No
Their surroundings are too warm / cold	Physical environment	No
They want something	Learned behaviour	No
They are angry	Emotional	Yes
There is nothing else for them to do	Stimulation	Yes
They live in a noisy place	Physical environment	No
They feel let down by somebody	Emotional	No
They are physically disabled	Biological	Yes
There is not much space in their house / classroom to move around in	Physical environment	Yes
They get left on their own	Stimulation	Yes
They are hungry or thirsty	Biological	Yes
They are frightened	Emotional	Yes
Somebody they dislike is nearby	Learned behaviour	No
People do not talk to them very much	Stimulation	No
They want to avoid uninteresting tasks	Learned behaviour	No
They do not go outdoors very much	Physical environment	Yes
They are rarely given activities to do	Stimulation	Yes
They want attention from other people	Learned behaviour	No
Total items in CHABA: 33	Total included: 19	

PHYSICAL ACTIVITY CHOICES- CARER QUESTIONNAIRE

We all make choices about our lifestyles. These choices might be about what we eat, the amount we eat, how active we are, how often we are active... The choices that we make can be influenced by a wide range of factors.

We are interested in what you think might influence the choices about physical activity that people with learning disabilities make.

This questionnaire includes a list of statements describing things that might influence the physical activity choices of people with learning disabilities.

For each statement, please think about how likely or unlikely it is to influence the choices of the person taking part in the walking intervention. Please circle a number to indicate your response for each of the statements.

	Very unlikely	Unlikely	Equally likely or unlikely	Likely	Very likely
1. The house where they live is too crowded with people	1	2	3	4	5
2. The person has physical health problems	1	2	3	4	5
3. They feel tired	1	2	3	4	5
4. The person finds it difficult to cope with stress	1	2	3	4	5
5. They are bored	1	2	3	4	5
6. Because of the medication that they are given	1	2	3	4	5
7. They feel unhappy	1	2	3	4	5
8. The area where they live is unpleasant	1	2	3	4	5
9. They enjoy being active	1	2	3	4	5
10. They are worried about something	1	2	3	4	5
11. They are angry	1	2	3	4	5
12. There is nothing else for them to do	1	2	3	4	5
13. There is not much space in their house to move around	1	2	3	4	5
14. They have mobility problems	1	2	3	4	5
15. They are on their own a lot	1	2	3	4	5
16. They are hungry or thirsty	1	2	3	4	5

17. They are frightened to take part in physical activity	1	2	3	4	5
18. They often lack support to choose activities they want to do	1	2	3	4	5
19. They do not go outdoors much	1	2	3	4	5

To what extent do you think that the person you support's choices about physical activity:

	Completely disagree	Mostly disagree	Slightly disagree	Neither	Somewhat agree	Mostly agree	Completely agree
20. Are related to something about him / her?	1	2	3	4	5	6	7
21. Change from day to day?	1	2	3	4	5	6	7
22. Are under his / her control?	1	2	3	4	5	6	7
23. Are the same in every situation?	1	2	3	4	5	6	7
24. Are exactly what he / she wants?	1	2	3	4	5	6	7

25. To what extent do you think that the person that you support could be helped to make positive changes to his / her choices about physical activity?

Definitely not	Probably not	Possibly not	Not sure	Possibly	Probably	Definitely
1	2	3	4	5	6	7

Scoring Criteria for the Physical Activity Choices Questionnaire

- Items 2, 3, 6, 14, 16 are summed to obtain the “Biological” subscale
(possible range = 5 – 25).
- Items 4, 7, 10, 11, 17 are summed to obtain the “Emotional” subscale
(possible range = 5 – 25).
- Items 1, 8, 13, 19 are summed to obtain the “Physical Environment”
subscale (Possible range = 4 – 20).
- Items 5, 9, 12, 15, 18 are summed to obtain the “Stimulation” subscale
(possible range = 5 – 25).

APPENDIX 9: SUPPLEMENTARY DATA

Frequency and percentage responses to items on the MCQ

	NO! Strongly disagree	No Disagree	? Undecided or unsure	Yes Agree	YES! Strongly agree
1. I really want the person that I support to make changes to their physical activity.	0	1/18 (5.6%)	7/18 (38.9%)	8/18 (44.4%)	2/18 (11.1%)
2. Sometimes I wonder if his / her levels of physical activity are a problem.	0	1/18 (5.6%)	4/18 (22.2%)	8/18 (44.4%)	5/18 (27.8%)
3. If he / she does not make changes to their activity levels soon, their health is going to get worse.	1/18 (5.6%)	2/18 (11.1%)	7/18 (38.9%)	3/18 (16.7%)	5/18 (27.8%)
4. I have already started to try to get him / her to make changes in their physical activity levels.	0	6/18 (33.3%)	1/18 (5.6%)	11/18 (61.1%)	0
5. His / her activity levels were a problem at one time, but they have managed to make changes.	1/18 (5.6%)	13/18 (72.2%)	1/18 (5.6%)	2/18 (11.1%)	1/18 (5.6%)
6. Sometimes I wonder if his / her activity levels are negatively affecting other people.	3/18 (16.7%)	5/18 (27.8%)	5/18 (27.8%)	5/18 (27.8%)	0
7. His / her physical activity levels are a problem.	0	4/18 (22.2%)	4/18 (22.2%)	6/18 (33.3%)	4/18 (22.2%)
8. I'm not just thinking about helping the person I support to make changes to their activity levels, I'm already doing something about it.	0	1/18 (5.6%)	9/18 (50.0%)	8/18 (44.4%)	0
9. The person I support has already made changes to their activities and needs to find ways to stop from slipping back into their old pattern.	7/18 (38.9%)	5/18 (27.8%)	4/18 (22.2%)	2/18 (11.1%)	0
10. He / she has serious problems related to their levels of activity.	1/18 (5.6%)	6/18 (33.3%)	4/18 (22.2%)	6/18 (33.3%)	1/18 (5.6%)
11. Sometimes I wonder if he / she is in control of the physical activity choices that they make.	0	7/18 (38.9%)	5/18 (27.8%)	5/18 (27.8%)	1/18 (5.6%)
12. His / her activity choices are causing a lot of harm.	1/18 (5.6%)	4/18 (22.2%)	7/18 (38.9%)	5/18 (27.8%)	1/18 (5.6%)
13. I am actively doing things to help him / her make positive changes to their physical activity.	0	2/18 (11.1%)	10/18 (55.6%)	6/18 (33.3%)	0

	NO! Strongly disagree	No Disagree	? Undecided or unsure	Yes Agree	YES! Strongly agree
14. I think that he / she needs to be coming to a service to get some help.	0	2/18 (11.1%)	3/18 (16.7%)	11/18 (61.1%)	2/18 (11.1%)
15. I know that his / her physical activity choices are a problem.	1/18 (5.6%)	1/18 (5.6%)	6/18 (33.3%)	8/18 (44.4%)	2/18 (11.1%)
16. I don't think that he / she has "a problem" with their activity choices, but there are times when I wonder if they should make healthier choices.	1/18 (5.6%)	8/18 (44.4%)	4/18 (22.2%)	5/18 (27.8%)	0
17. He / she has an unhealthy lifestyle.	0	2/18 (11.1%)	4/18 (22.2%)	10/18 (55.6%)	2/18 (11.1%)
18. I am working hard to make change happen.	0	0	9/18 (50.0%)	9/18 (50.0%)	0
19. There has already been some progress in making positive changes to his / her choices about physical activity.	3/18 (16.7%)	4/18 (22.2%)	2/18 (11.1%)	9/18 (50.0%)	0

20. How important would you say it is for the person that you care for to make changes to their levels of physical activity?

0	1	2	3	4	5	6	7	8	9	10
0	0	0	1/18 (5.6%)	1/18 (5.6%)	1/18 (5.6%)	3/18 (16.7%)	3/18 (16.7%)	3/18 (16.7%)	3/18 (16.7%)	3/18 (16.7%)

21. How confident would you say you are that if the person that you care for wanted to make changes to their activity levels, they could do it?

0	1	2	3	4	5	6	7	8	9	10
2/18 (11.1%)	2/18 (11.1%)	2/18 (11.1%)	1/18 (5.6%)	2/18 (11.1%)	3/18 (16.7%)	2/18 (11.1%)	3/18 (16.7%)	1/18 (5.6%)	0	0

Frequency and percentage responses to items on the PACQ

Attribution	Very unlikely	Unlikely	Equally likely or unlikely	Likely	Very likely
1. The house where they live is too crowded with people	4/18 (22.2%)	8/18 (44.4%)	3/18 (16.7%)	1/18 (5.6%)	2/18 (11.1%)
2. The person has physical health problems	0	7/18 (38.9%)	0	7/18 (38.9%)	4/18 (22.2%)
3. They feel tired	0	3/18 (16.7%)	1/18 (5.6%)	10/18 (55.6%)	4/18 (22.2%)
4. The person finds it difficult to cope with stress	0	2/18 (11.1%)	4/18 (22.2%)	9/18 (50.0%)	3/18 (16.7%)
5. They are bored	0	7/18 (38.9%)	7/18 (38.9%)	4/18 (22.2%)	0
6. Because of the medication that they are given	4/18 (22.2%)	8/18 (44.4%)	3/18 (16.7%)	3/18 (16.7%)	0
7. They feel unhappy	0	4/18 (22.2%)	7/18 (38.9%)	7/18 (38.9%)	0
8. The area where they live is unpleasant	1/18 (5.6%)	9/18 (50.0%)	3/18 (16.7%)	3/18 (16.7%)	2/18 (11.1%)
9. They enjoy being active	0	8/18 (44.4%)	5/18 (27.8%)	3/18 (16.7%)	2/18 (11.1%)
10. They are worried about something	0	3/18 (16.7%)	12/18 (66.7%)	3/18 (16.7%)	0
11. They are angry	0	5/18 (27.8%)	7/18 (38.9%)	4/18 (22.2%)	2/18 (11.1%)
12. There is nothing else for them to do	0	4/18 (22.2%)	11/18 (61.1%)	2/18 (11.1%)	1/18 (5.6%)
13. There is not much space in their house to move around	0	10/18 (55.6%)	3/18 (16.7%)	4/18 (22.2%)	1/18 (5.6%)
14. They have mobility problems	4/18 (22.2%)	1/18 (5.6%)	3/18 (16.7%)	10/18 (55.6%)	0
15. They are on their own a lot	2/18 (11.1%)	12/18 (66.7%)	1/18 (5.6%)	2/18 (11.1%)	1/18 (5.6%)
16. They are hungry or thirsty	1/18 (5.6%)	3/18 (16.7%)	13/18 (72.2%)	1/18 (5.6%)	0
17. They are frightened to take part in physical activity	1/18 (5.6%)	3/18 (16.7%)	7/18 (38.9%)	5/18 (27.8%)	2/18 (11.1%)
18. They often lack support to choose activities they want to do	0	5/18 (27.8%)	6/18 (33.3%)	6/18 (33.3%)	1/18 (5.6%)

Attribution	Very unlikely	Unlikely	Equally likely or unlikely	Likely	Very likely
19. They do not go outdoors much	1/18 (5.6%)	3/18 (16.7%)	3/18 (16.7%)	5/18 (27.8%)	6/18 (33.3%)

	Completely disagree	Mostly disagree	Slightly disagree	Neither	Somewhat agree	Mostly agree	Completely agree
20. Are related to something about him / her? (Locus)	0	2/18 (11.1%)	2/18 (11.1%)	1/18 (5.6%)	7/18 (38.9%)	5/18 (27.8%)	1/18 (5.6%)
21. Change from day to day? (Stability)	0	2/18 (11.1%)	6/18 (33.3%)	7/18 (38.9%)	1/18 (5.6%)	2/18 (11.1%)	0
22. Are under his / her control? (Controllability)	1/18 (5.6%)	2/18 (11.1%)	1/18 (5.6%)	3/18 (16.7%)	9/18 (50.0%)	1/18 (5.6%)	1/18 (5.6%)
23. Are the same in every situation? (Globality)	0	1/18 (5.6%)	3/18 (16.7%)	14/18 (77.8%)	0	0	0
24. Are exactly what he / she wants? (Intentionality)	1/18 (5.6%)	3/18 (16.7%)	4/18 (22.2%)	5/18 (27.8%)	3/18 (16.7%)	2/18 (11.1%)	0

25. To what extent do you think that the person that you support could be helped to make positive changes to his / her choices about physical activity?

	Definitely not	Probably not	Possibly not	Not sure	Possibly	Probably	Definitely
Treatment optimism	0	4/18 (22.2%)	0	4/18 (22.2%)	5/18 (27.8%)	4/18 (22.2%)	1/18 (5.6%)

APPENDIX 10: ETHICAL / RESEARCH AND DEVELOPMENT APPROVAL LETTERS

Scotland A Research Ethics Committee

Secretariat
2nd Floor Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone: 0131 465 5680
Fax: 0131 465 5789
www.nres.nhs.uk



Dr Craig Melville
Senior Lecturer in Learning Disabilities
Psychiatry
University of Glasgow
Mental Health & Wellbeing
Gartnavel Royal Hospital
Glasgow
G12 0XH

Date: 31 January 2012
Your Ref.:
Our Ref.: 12/SS/0003
Enquiries to: Walter Hunter
Extension: 35680
Direct Line: 0131 465 5680
Email: walter.hunter@nhslothian.scot.nhs.uk

Dear Dr Melville

Study title: The impact of a walking intervention on the physical activity levels and health of adults with learning disabilities

REC reference: 12/SS/0003

The Scotland A Research Ethics Committee reviewed the above application at the meeting held on 26 January 2012. Thank you for attending to discuss the study.

Ethical opinion

The Committee noted this was a doctoral thesis in psychology looking to ascertain the impact of a structured walking programme on participants with learning disabilities. The study design involved a single blind, randomised control trial intervention to test a variety of null hypotheses to minimise bias of 'participant effect'. Potential participants who indicate an interest would be visited, most likely in their home but a choice of venues would be offered. The Committee was unclear about what was meant by 'waiting list control group'. The application form provided little information about the likely nature of the walking programme but the protocol suggested the aim was to increase daily walking by thirty minutes by week twelve. There was a reference in the participant information sheet to walking with friends or carers as well as walking further to the bus stop or walking for leisure at the weekend. The Committee considered that the inclusion of adults lacking capacity had been justified given the need for a full range of participation to judge the effect of the benefits of intervention and carer guidance. The Committee considered the study was worthwhile but recognised there was heavy carer involvement and support to make it work. The information sheets were considered to be good although some minor

Chairman Dr Ian Zealley
Vice-Chairman Dr Colin Selby

changes were identified. The Committee noted that the sample size was small and wondered if this was sufficiently robust to provide a meaningful outcome. However they were reassured by the statistical input to the study.

Dr Melville and Mrs Grant attended to discuss the study. Dr Melville explained at the outset that Mrs Grant's involvement in the study was to look at behavioural change which linked to her degree course; the remainder of the study was his project. Dr Melville was asked about the venue for the visits and confirmed that it was likely to be a home visit. In being asked what was meant by 'waiting list control group' Dr Melville advised that this was a waiting list within the study. Those on the waiting list would form the control group and would be offered the intervention after three months. The researchers would use data collected at base and then after three months after the control stage. The Committee advised that the roles and involvement of controls should be mentioned in the information sheets. The Committee asked about the burden on carers for data gathering. Dr Melville accepted this was the case as borne out by previous studies and explained that behaviour studies were very dependent on the carer. Dr Melville was asked if they were missing an opportunity to collect 'harder endpoints', particularly in relation to health benefits but indicated that they were not looking to go beyond the aims set out in the application form and protocol. The first outcome was to establish if the intervention period was too short based on a three month intervention followed by a three month follow-up period. In response to being asked about the recruitment process Dr Melville said they would be approaching those who were service users. There would be some recruitment from those requiring healthcare and/or those with little support provided by the community or having paid carers. Dr Melville further mentioned they would not be asking health providers or social work to identify potential participants from their databases; the aim was to use those known to use services or receiving paid care.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Adults with Incapacity (Scotland) Act 2000

I confirm that the Committee has approved this research project for the purposes of the Adults with Incapacity (Scotland) Act 2000. The Committee is satisfied that the requirements of section 51 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non NHS sites

The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. I will write to you again as soon as one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at non-NHS sites.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Other conditions specified by the REC

1. The participant information sheet should:
 1. mention that walks could be with carers as well as friends
 2. make reference to 'pedometer' in the paragraph relating to 'special belt' on page two
 3. explain who Andrew Jahoda was
 4. correct spelling of 'programme' throughout
 5. mention the role of the controls and process for their involvement
 6. the consent forms should:
 7. seek specific consent for permission to involve a carer.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter		04 January 2012
REC application: IRAS Form	3.4	20 December 2011
Protocol	1.1	15 December 2011
Investigator CV: Dr C Melville		
Investigator CV: Mrs K Grant		
Letter of invitation to participant	1.1	15 December 2011
Participant Information Sheet: Participant	1.1	15 December 2011
Participant Consent Form: Participant	1.1	15 December 2011
Participant Information Sheet: Welfare Guardian/Nearest Relative	1.1	15 December 2011
Participant Consent Form: Welfare Guardian/Nearest	1.1	15 December 2011

Relative		
Participant Information Sheet: Carer	1.1	15 December 2011
Participant Consent Form: Carer	1.1	15 December 2011
GP/Consultant Information Sheets	1.1	15 December 2011
Interview Schedules/Topic Guides	1.1	15 December 2011
Other: Letter from Funder		11 February 2011

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

REC reference number: 12/SS/0003-Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Ian Zealley'.

Dr Ian Zealley
Committee Chairman

cc: Dr Erica Packard, NHS Greater Glasgow and Clyde
Mrs K Grant

Coordinator/Administrator: Dr Erica Packard/Mrs Elaine O'Neill
Telephone Number: 0141 211 6208
E-Mail: erica.packard@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d

R&D Management Office
Western Infirmary
Tennent Institute
1st Floor 38 Church Street
Glasgow, G11 6NT,

16 March 2012

Dr Craig Melville
University of Glasgow
Mental Health and Wellbeing
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow G12 0XH

NHS GG&C Board Approval

Dear Dr Melville,

Study Title:	The impact of a walking intervention of the physical activity levels and health of adults with learning disabilities
Principal Investigator:	Dr Craig Melville
GG&C HB site	Learning Disabilities Services
Sponsor	NHS Greater Glasgow and Clyde
R&D reference:	GN11LD061
REC reference:	12/SS/0003
Protocol no:	V1.1; 15/12/11
(including version and date)	

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study. **Please note that this approval does not include the research assistant, yet to be appointed.**

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
 - a. During the life span of the study GGHB requires the following information relating to this site
 - i. Notification of any potential serious breaches.
 - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

Delivering better health

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Page 1 of 2

R&D Approval GN11LD061

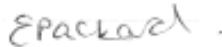
2. **For all studies** the following information is required during their lifespan.
- a. Recruitment Numbers on a quarterly basis
 - b. Any change of staff named on the original SSI form
 - c. Any amendments – Substantial or Non Substantial
 - d. Notification of Trial/study end including final recruitment figures
 - e. Final Report & Copies of Publications/Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,



Dr Erica Packard
Research Co-ordinator

Abstract

Background

Studies have shown a higher prevalence of obesity and lower levels of physical activity among individuals with learning disabilities compared with the general population, which highlights the need for effective interventions and clinical services for individuals with learning disabilities and obesity. Carers and families have a key role to play in identifying and responding to the health needs of individuals with learning disabilities. Attribution theory has previously been utilised in studies investigating carers' attributions around challenging behaviour in individuals with learning disabilities. In relation to individuals with learning disabilities and obesity, carers' attributions might be important mediators of their motivation to support change in the individual that they support, and thus may influence help seeking and adherence to interventions.

Aims

- To investigate carers' causal attributions about physical activity behaviours related to obesity / overweight in adults with learning disabilities.
- To examine whether carers' attributions around physical activity are linked to their motivations to support the individual whom they provide care for to engage in interventions.
- To explore whether carers' attributions are influenced by gender and / or level of learning disability of the individuals that they provide care for.

Methods

A between subjects questionnaire design will be used to investigate carers' attributions of physical activity and explore how these relate to their motivation to support change. The influence of gender and level of learning disability of the individual that the carer supports will be examined in relation to carers' attributions.

Applications

Exploring the relationship between carers' attributions and their motivation to support change will potentially highlight barriers to change, which might impact upon the implementation of effective services for individuals with learning disabilities and obesity. If this is the case then the findings of this study could be used to inform training programmes for carers.

Introduction

Obesity is recognised as a major public health concern internationally (World Health Organisation, 2004) and there is clear evidence that obesity has a negative impact upon health (Kopelman, 2007). Several studies examining the prevalence of obesity in individuals with learning disabilities have found higher rates of obesity compared with rates of obesity derived from studies involving the general population (Emerson, 2005; Melville et al., 2006; Melville et al., 2008).

A lack of regular physical activity can contribute to obesity. Finlayson et al. (2009) investigated individuals with learning disabilities' participation in physical activity. It was found that individuals with learning disabilities were significantly less likely than the general population to meet the recommended levels of physical activity set out by the Scottish Executive (2003). Only five percent of the total sample met the recommendation of at least 30 minutes of at least moderate activity on a minimum of five days per week.

Thus, findings that indicate a higher prevalence of obesity and lower levels of physical activity among individuals with learning disabilities compared with the general population highlight the need for effective interventions and clinical services for individuals with learning disabilities and obesity. However, individuals with learning disabilities have problems accessing mainstream clinical services for obesity and weight management (NHS Health Scotland, 2004). Moreover, interventions and services designed for the general population may not be effective when working with individuals with learning disabilities. Thus, it is important to develop and

investigate the effectiveness of weight loss interventions for individuals with learning disabilities (Hamilton et al., 2007).

Carer involvement

Individuals with learning disabilities can be reliant on carers to identify their health needs and support them in accessing services. In addition, carers have an important role in supporting the individual that they provide care for to make healthy lifestyle choices. Therefore, it follows that carers' motivation will have a bearing on the effectiveness of interventions for obesity. It is important that carers are able to recognise the health risks associated with obesity and the benefits associated with interventions, and that they are prepared to support the individuals that they provide care for to engage in interventions.

The important role that carers can play was highlighted by Fox et al. (1985) who investigated the impact of parent involvement on the outcomes of a behavioural weight loss programme for individuals with learning disabilities. It was found that individuals whose parents were actively involved in the programme lost significantly more weight than individuals whose parents were minimally involved in the programme. Building upon the work of Fox et al. (1985), McCarran & Andrasik (1990) conducted a study further investigating the impact of involving parents / carers in a weight-loss programme. Although they did not observe significant differences between the two groups, it was found that clinical outcomes were slightly better and weight loss was better maintained in the group for whom there was involvement from parents / carers. Small numbers in this study might have contributed to the failure to detect significant differences. Taken together, the results

of these studies highlight the important role that carers have in supporting individuals with learning disabilities to engage in interventions for obesity.

Hamilton et al. (2007) highlighted the importance of considering the role of carers when thinking about developing weight loss interventions for individuals with learning disabilities. Finlayson et al. (2009) also proposed that it is important to involve carers in increasing and supporting participation in physical activity by individuals with learning disabilities. Thomas & Kerr (2011) conducted a study investigating long-term outcomes for individuals with learning disabilities following participation in a health promotion programme which aimed to increase physical activity levels in individuals with learning disabilities. It was found that 69% of the sample was overweight / obese. Although individuals with learning disabilities and their carers initially appeared keen to participate in the programme, rates of non-attendance at follow-up clinics were high (21% at one year follow up; 34% at two year follow up). Carers in this study were asked to indicate what they perceived to be the barriers to access for the individuals that they provided support for and not wanting to disrupt the client's day was cited as one of the main reasons for non-attendance, which suggests that carers may not recognise the importance of interventions for obesity.

Carers' attributions

Weiner (1980) proposed that individuals make causal attributions in order to explain behaviour. He stated that all causal attributions can be characterised across three dimensions; locus (behaviour caused by internal or external factors), stability (whether behaviour is enduring or temporary) and controllability (behaviour either

under control or uncontrollable). These causal attributions invoke an emotional reaction in the individual, which determines subsequent behaviour. Thus it is how behaviour is causally attributed and not the behaviour itself that determines subsequent reactions.

There is limited research exploring attributions around obesity and health behaviour change in carers of individuals with learning disabilities. However, Melville et al. (2009) conducted a study exploring carers' attributions around the benefits of public health recommendations relating to diet and physical activity and barriers to achieving these recommendations for individuals with learning disabilities. It was found that carers tended to have a low level of knowledge around public health recommendations regarding diet and physical activity. The majority of carers reported that they thought that the person that they supported would benefit from eating a healthier diet and increasing their levels of physical activity. Carers reported recognising a range of health benefits associated with healthy lifestyles, as well as benefits relating to quality of life. Benefits relating to self-image were rated as being of lower importance than health and quality of life benefits.

When asked about what they perceived to be barriers to adopting healthier lifestyles for individuals with learning disabilities, carers were found to be more likely to rate intrapersonal barriers, such as lack of knowledge and skills and motivation for change as important, rather than interpersonal and external barriers to change. This suggests that carers perhaps did not recognise significant interpersonal and external barriers to change for individuals with learning disabilities, instead perceiving the main barriers for change within the individual.

The findings of Melville et al. (2009) that carers were more likely to identify factors within the individual as main barriers to change might be related to their attributions about obesity and the causes of this in the individuals that they care for. Such attributions might be important mediators of their decision to seek treatment, and attributions may also influence adherence to interventions.

Motivation of carers

Weiner's Attribution Model (1980) has not previously been applied to the study of obesity, however, it has been utilised in previous studies (e.g. Wanless & Jahoda, 2002) investigating carers' attributions around challenging behaviour in individuals with learning disabilities. With regard to individuals with learning disabilities and obesity, Weiner's model would suggest that if carers view the behaviour of individuals, such as making unhealthy food choices or having low physical activity levels, as internal, stable and uncontrollable, this might impact upon their own motivation to facilitate change. Thus, they might be less likely to seek help and adhere to interventions.

Previous studies have highlighted the fact that carer attributions may present a barrier to individuals with learning disabilities participating in physical activity (Frey et al., 2005). It is likely that, if carers do not recognise the health benefits of physical activity, then this will impact upon their motivation to support individuals with learning disabilities to engage in physical activity. Melville et al. (2009) found that carers more readily identified health benefits associated with a healthy diet than health benefits of physical activity. This might be reflective of carers' own perceptions of physical activity as well as their views on the participation of

individuals with learning disabilities in physical activity, which might also impact upon motivation levels.

In summary, obesity presents a significant problem for many individuals with learning disabilities. Carers and families have a key role to play in identifying and responding to the health needs of the individuals that they care for. Carers' attributions potentially have an impact upon the likelihood of them supporting the individual that they care for to access interventions for obesity and facilitating engagement and adherence to treatment programmes. The current study will explore carers' attributions around obesity and lifestyle behaviours related to obesity / overweight in adults with learning disabilities. It will also examine whether attributions are linked to carers' motivations to support change in the individuals whom they provide care for.

Aims and Research Questions

Aims:

- To investigate carers' causal attributions about physical activity behaviours related to obesity / overweight in adults with learning disabilities.
- To examine whether carers' attributions around physical activity are linked to their motivations to support the individual whom they provide care for to engage in interventions.
- To explore whether carers' attributions are influenced by gender and / or level of learning disability of the individuals that they provide care for.

Research questions:

- 1) To what extent do family carers and paid carers differ in terms of their attributions about physical activity behaviours related to obesity / overweight in adults with learning disabilities?
- 2) To what extent do family carers and paid carers differ in terms of their motivation to support the individual that they provide care for to engage in lifestyle behaviour changes?
- 3) Is there a significant correlation between carers' attributions and their motivation to support change?
- 4) Is there a relationship between carer attributions and i) gender of the individual that they provide care for; ii) level of learning disability of the individual that they provide care for.

Plan of investigation

➤ Design

This study will employ a quantitative, between-participants questionnaire design to investigate carers' attributions of physical activity and explore how these relate to their motivation to support change. The influence of gender and level of learning disability of the individual that the carer supports will be examined in relation to carers' attributions.

Carers of individuals who are obese / overweight will be asked to consider the individual for whom they provide care. Bearing this person in mind, carers will be asked to complete questionnaires assessing their attributions of physical activity and ratings of motivation to support change. Demographic information will also be collected.

➤ Participants

Participants will be carers of adults with learning disabilities who are overweight / obese (both paid carers and family carers).

➤ Inclusion and exclusion criteria

Participants will include both family carers and paid carers of individuals with learning disabilities who have a BMI of >25. Participants will be required to have a good grasp of the English language.

➤ Recruitment procedures

This study will be linked to another research project aiming to increase the physical activity levels of individuals with learning disabilities and obesity. The carers of the participants in this research project will be approached and invited to participate in the present study. Participants will be provided with information about the present study, and informed consent will be sought.

It is anticipated that the majority of questionnaires will be collected by the researcher at the point of completion. However, if this is not possible, prepaid envelopes will be

made available and / or it will be arranged that the researcher will collect the questionnaires at a later date.

➤ Measures

Attributions

Previous research looking at carers' attributions has utilised vignette methodologies. However, research (e.g. Wanless and Jahoda, 2002) has highlighted the fact that vignettes may provide limited insight into the appraisals staff make, and ratings related to vignettes may differ significantly from ratings relating to actual events. Thus, in order to assess carers' attributions around behaviours related to obesity, carers will be asked to consider the individual that they provide care for when completing the rating scales.

The attributions questionnaire will be adapted from Hastings' (1997) Challenging Behaviour Attributions Scale (CHABA), which was designed to explore staff attributions around challenging behaviour. This questionnaire comprises 33 items, which relate to five causal models: learned behaviour; biomedical; emotional; physical environment and stimulation. The CHABA has been shown to have acceptable levels of reliability (Hastings, 1997).

The adapted scale will be utilised to assess carers' attributions of physical activity behaviours related to obesity / overweight in individuals with learning disabilities. Participants will be required to make attributions in relation to the causal models identified by the CHABA and along Weiner's (1980) dimensions of locus, stability and controllability. Attributions will be measured using a bipolar scale.

Motivation

A rating scale will also be utilised to assess carers' motivation to change. This will be adapted from The Stages of Change Readiness and Treatment Eagerness Scale (SOCRATES; Miller & Tonigan, 1996). SOCRATES was originally designed to assess readiness for change in individuals with alcohol misuse problems. The measure provides three scale scores: Recognition, Ambivalence and Taking Steps. SOCRATES has been shown to have high levels of validity and reliability (Miller & Tonigan, 1996). A parallel 'Significant Other' scale has been developed to assess the motivation of significant others. It is proposed that this scale will be adapted for the purposes of this study. The SOCRATES 'Significant Other' scale comprises 32 items and, like the SOCRATES, it yields three scale scores (Recognition, Ambivalence and Taking Steps).

In addition to the scale adapted from the SOCRATES 'Significant Other' scale, participants will be asked to provide ratings of the importance of change, and their confidence in their ability to support change in the individual whom they provide support for. These ratings will be on a 10-point scale. Importance and confidence have been identified as important predictors of readiness for change.

Demographic Information

Demographic information will also be collected and will include: type of carer (paid / family carer); gender of the individual whom the carer supports; age of the individual whom the carer supports; level of learning disability of the individual whom the carer supports.

➤ Research procedures

The researcher will meet potential participants who will be informed of the study both verbally and through the provision of an information sheet. Following this, consent will be requested. Participants will then complete questionnaires relating to attributions, motivation to support change and demographic information. Data from questionnaires will be coded and stored anonymously on an encrypted laptop.

➤ Justification of sample size

As no previous study has examined the relationship between carer attributions and motivation there is no data available to do a formal sample size calculation. This exploratory study will examine this relationship and gather data that can be used in power calculations for future studies. Moreover, no previous studies have compared family carers and paid carers.

The proposed sample size for the exploratory study is 30. It is planned that 15 family carers and 15 paid carers will be recruited. This will provide sufficient variability within participants to reduce bias, and give a reliable estimate of the relationship between the variables.

➤ Settings and equipment

The questionnaires will be completed by participants in day centre settings, which are staffed.

Paper will be required to prepare questionnaires. Prepaid envelopes may be required to enable carers to return questionnaires.

➤ Data analysis

Quantitative analysis will be conducted using SPSS. Descriptive statistics will be prepared initially. Data will be assessed for normality, and will be transformed if required. Student t-tests and correlation will be utilised to analyse data.

Health and Safety Issues

➤ Researcher safety issues

The Glasgow University Mental Health and Wellbeing Unit researcher lone working policy will be adhered to at all times. Meetings with participants will be conducted in community locations. Moreover, as all potential participants will be known to learning disabilities services, staff will be asked to indicate any potential risks.

➤ Participant safety issues

Participants will be given an information sheet providing details of the study and they will have the opportunity to ask any questions that they may have before consent is obtained. Following participation, participants will be provided with an opportunity to discuss any issues that may have arisen or to ask any questions that they might have. Participants will be given the option of having a summary of the results sent to them following completion of the project.

It is not anticipated that completing the questionnaires will cause participants distress; however, it is possible that participants might become distressed if they become aware of difficulties that the person that they support may have, which they had not previously thought about, such as weight problems. If this is the case, participants will be encouraged to access primary care services and specialist learning disability health specialists, if appropriate. If participants are not satisfied with this, they will be provided with the opportunity to contact Dr Melville (Research Supervisor) who has expertise in managing the health needs of individuals with learning disabilities.

Ethical issues

A participant information sheet will be devised and informed consent will be sought from all participants. Participants will be provided with an opportunity to discuss any issues that may have arisen or to ask any questions that they might have following participation. All raw data will be anonymised and stored on an encrypted laptop. Formal ethical approval for the study will be sought from the Scotland A Research Ethics Committee; NHS Greater Glasgow & Clyde Ethics Committee and Research & Development.

Financial issues

Costs associated with this study include the cost of paper to prepare questionnaires and prepaid envelopes for participants to return questionnaires.

Timetable

January 2011: submit draft proposal

February 2011 – May 2011: develop and revise draft proposal

May 2011: submit final proposal

July 2011: submit application for ethical approval

October 2011: obtain ethical approval

October 2011 – January 2012: recruitment and data collection

February 2012 – April 2012: data analysis

May 2012 – July 2012: write up

Practical applications

Exploring the associations between carers' causal attributions of obesity in individuals with learning disabilities and their motivation to support change will potentially highlight barriers to change, which might impact upon the ability of individuals with learning disabilities, to engage in interventions. It is hoped that this research will add to previous studies exploring obesity and weight loss in individuals with learning disabilities, and add to the findings of previous studies which have investigated the role of carers in supporting individuals with learning disabilities and obesity. There may be implications for training programmes for carers.

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